DEPARTMENT OF PSYCHOLOGY

THE UNPLANNED JOURNEY:
PARENTS' MEANING ON THEIR CHILDREN'S DEVELOPMENTAL DISABILITY

DOCTOR OF PHILOSOPHY DISSERTATION

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DEPARTMENT OF PSYCHOLOGY

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ELENI K. DIMITRIOU

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The present doctoral dissertation was submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy of the University of Cyprus. It is a product of original work of my own, unless otherwise mentioned through references, notes, or any other statements.

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Abstract in Greek

Η νοηματοδότηση της αναπηρίας από γονείς παιδιών με αναπτυξιακές διαταραχές. Ένα απροσδόκητο ταξίδι.

Ελένη Δημητρίου

Οι γονείς που μεγαλώνουν παιδιά με αναπτυξιακές διαταραχές αντιμετωπίζουν πολλαπλές προκλήσεις. Στόχος της έρευνας αυτής είναι να διερευνήσει το υποκειμενικό νόημα των γονιών που μεγαλώνουν παιδιά με αναπτυξιακές διαταραχές κατά τη διάρκεια του βιώματός τους ως γονείς. Συγκεκριμένα, θα εξεταστεί ο τρόπος που οι γονείς βιώνουν και νοηματοδοτούν την εμπειρία τους και ο τρόπος που διαχειρίζονται τις προκλήσεις της γονεϊκότητας.

Προσεγγίζω την εμπειρία κάθε γονιού ως μια μοναδική ιστορία ζωής, αναδεικνύοντας παράλληλα τις κοινές διεργασίες που βιώνουν διαφορετικοί γονείς καθώς μεγαλώνουν τα παιδιά τους με αναπτυξιακές διαταραχές. Η αναπηρία λογίζεται ως ρήξη για τους γονείς στην έρευνα αυτή, ως μια διατάραξη στην κανονική ροή της ζωής τους, που παράγει αβεβαιότητα και ανισορροπία. Σύμφωνα με τη θεωρία των συμβολικών πόρων (Zittoun, 2006), οι ρήξεις ακολουθούνται από μεταβάσεις, οι οποίες αποτελούν διαδικασίες επανατοποθέτησης με σκοπό την οικοδόμηση νέου νοήματος για τον κόσμο και τον εαυτό. Διερευνώ ευρύτερα τις διαδικασίες επανα-νοηματοδότησης της ζωής τους αλλά και πιο συγκεκριμένα τη χρήση συμβολικών πόρων προκειμένου να ανταπεξέλθουν σε αυτή τη μετάβαση και να χτίσουν νόημα για την γονεϊκή τους εμπειρία. Η εμπειρία των γονιών θεωρείται κοινωνικά και πολιτισμικά πλαισιωμένη: τοποθετείται εντός του κοινωνικού πλαισίου στο οποίο ζουν και ενεργούν οι γονείς και διερευνάται ο τρόπος που οι κοινωνικές αναπαραστάσεις του πλαισίου επηρεάζουν την εμπειρία τους (Moscovici, 1984; Duveen & Lloyd, 1990).

Για την έρευνα αυτή χρησιμοποίησα ποιοτική μεθοδολογία, ως την καταλληλότερη μέθοδο για να κατανοήσω τη διαδικασία της νοηματοδότησης και για να διερευνήσω πώς οι γονείς βιώνουν τις αναπτυξιακές διαταραχές των παιδιών τους μέσα στο συγκεκριμένο κοινωνικο-πολιτισμικό περιβάλλον. Πήρα συνεντεύξεις από 26 γονείς, μητέρες και πατέρες παιδιών με διάφορες αναπτυξιακές διαταραχές, εστιάζοντας στα ορόσημα της γονεϊκής εμπειρίας, στα νοήματα, τα συναισθήματα και τους πόρους που χρησιμοποιούν οι γονείς αλλά και τις προκλήσεις που σχετίζονται με την αίσθηση του εαυτού και των κοινωνικών τους ρόλων. Ανέλυσα τα δεδομένα από τις αφηγήσεις των γονέων με τη χρήση θεματικής ανάλυσης.

Τα αποτελέσματα της έρευνας δείχνουν ότι, όσον αφορά τα ορόσημα του βιώματος των γονιών, οι γονείς βιώνουν μια συνεχή διεργασία διαπραγμάτευσης της διάγνωσης των παιδιών τους, και όχι μια ξεκάθαρη αποδοχή ή απόρριψη της διάγνωσης, όπως πρότειναν προηγούμενες έρευνες (Hugger, 2009; Boström et al, 2010). Ταυτόχρονα, οι γονείς έρχονται αντιμέτωποι με την αναπαράσταση της διάγνωσης των παιδιών τους ως πρόβλημα, την οποία διαπραγματεύονται και τελικά αποδομούν. Όσον αφορά την εμπειρία της γονεϊκότητας, προτείνω ότι το βίωμα των γονιών αποτυπώνεται σε μια σπειροειδή μορφή, καθώς φαινομενικά αντίθετα συναισθήματα και νοήματα διαδέχονται το ένα το άλλο, δηλαδή οι γονείς βιώνουν όφελος αλλά και απώλεια, ευλογία αλλά και βάρος. Παρά το βάρος και την αβεβαιότητα που βιώνουν οι γονείς, αντιμετωπίζουν τη ρήξη της αναπηρίας των παιδιών τους αντλώντας από ευρύτερα κοινωνικά νοήματα (για παράδειγμα νοηματοδοτώντας την αναπηρία του παιδιού τους ως ευλογία) αλλά και μέσω της χρήσης συγκεκριμένων συμβολικών πόρων, όπως ένα ιστολόγιο (blog) και η θρησκεία. Η χρήση των συμβολικών πόρων επιτρέπει στους γονείς να αντιμετωπίσουν αυτή τη ρήξη, να δημιουργήσουν νόημα για την αναπηρία των παιδιών τους και να προχωρήσουν πέρα από τη διατάραξη που δημιούργησε αυτή η μετάβαση, αναπτύσσοντας μια ελπιδοφόρα προοπτική για το μέλλον. Παράλληλα, η επαφή με άλλους γονείς φαίνεται να λειτουργεί ως ‘μηχανισμός κανονικοποίησης’ (‘normalization’) για τους γονείς.

Ολοκληρώνω αυτή την έρευνα με τη συζήτηση της συμβολής των αποτελεσμάτων στην υπάρχουσα βιβλιογραφία. Αυτή η μελέτη εισάγει την ιδέα μιας δια βίου διεργασίας ρήξης, την οποία βιώνουν οι γονείς που μεγαλώνουν παιδιά με αναπτυξιακές διαταραχές μέσα στο συγκεκριμένο κοινωνικο-πολιτισμικό πλαίσιο. Όσον αφορά τη δημιουργία νοήματος, οι γονείς κατασκευάζουν δίπολα αντίθετων νοημάτων καθ’ όλη τη διάρκεια της γονεϊκής τους εμπειρία. Όσον αφορά τις στρατηγικές αντιμετώπισης που χρησιμοποιούν οι γονείς, αυτές περιλαμβάνουν τη δημιουργία νοήματος (νοηματοδότηση) ως στρατηγική αντιμετώπισης, τη χρήση συμβολικών πόρων και άλλες πρακτικές στρατηγικές αντιμετώπισης, όπως η συγκέντρωση πρακτικής γνώσης και η υποστήριξη από άλλους γονείς. Τέλος, αυτή η έρευνα προτείνει πρακτικές εισηγήσεις, συζητά ορισμένους ερευνητικούς περιορισμούς που εντοπίστηκαν και θέτει μελλοντικές κατευθύνσεις για έρευνα.

Abstract in English

The unplanned journey. Parents’ meaning on their children’s developmental disability.

Eleni Dimitriou

The experience of parenting a child with developmental disability generates multiple challenges for the parents. The aim of this research is to explore the subjective meaning of parents throughout the journey of raising their children with developmental disabilities.

I approach parents’ experiences as unique life stories, focusing at the same time on the common processes different parents who raise children with developmental disabilities go through. In this research, disability is considered a rupture for parents, a disruption in the regular flow of their life, producing uncertainty and imbalance. According to the theoretical framework of symbolic resources (Zittoun, 2006), ruptures are followed by transitions, processes of repositioning in order to build new meaning towards the world and the self. I explore whether parents make use of any resources in order to cope through this transition and construct meaning upon their experience of parenting. Additionally, Parents’ experience is considered as socio-culturally embedded: it is situated in the social context in which parents live and act and the way that social representations of the context affect their experience is examined (Moscovici, 1984; Duveen & Lloyd, 1990).

I used qualitative methodology for this research, as the most suitable approach to understand the process of meaning-making and to explore how parents experience their children’s developmental disabilities within the specific socio-cultural milieu. I interviewed 26 parents, mothers and fathers of children with several developmental disabilities, exploring the milestones of their course of parenting, their experience in terms of meanings, feelings and resources and the self-related challenges they face. I analysed the data collected from the parents' narratives using thematic analysis.

The findings indicate that, regarding the milestones of the parenting experience, the parents experience an ongoing process of negotiating their children's diagnosis, instead of straightforwardly accepting or rejecting it, as previous research suggested (Hugger, 2009; Boström et al, 2010). At the same time, parents are challenged by the representation of their children’s diagnosis as a problem, which they negotiate and eventually deconstruct. As to their experience of parenting, I suggest that parents raise their children within a parenting course of a spiral nature, where seemingly opposite feelings and meanings succeed one another, such as gain and loss or blessing and burden. Despite the burden and the uncertainty that parents experience, they deal with the rupture of their children’s disability by more generally creating new meanings (such as their children’s disability as a blessing) and more specifically using symbolic resources, such as a blog and religion. The use of symbolic resources allows parents to cope with this rupture, to create meaning on their children's disability and to move beyond the disruption that this transition created, developing a hopeful perspective towards the future. Concurrently, the contact with other parents seems to function as a 'normalization' coping mechanism for parents. With regards to the parents' self-related issues, I suggest that the experience of parenting a child with developmental disabilities has a transformative effect on parents. Additionally, the parents build a new social self of solidarity through sharing their experience with other parents.

I close this study with the discussion of the contribution of these findings to existing literature. This study introduces the idea of a lifelong rupture process, which parents raising children with developmental disabilities within the particular socio-cultural context experience. In terms of meaning-making, parents construct dipoles of oppositional meanings throughout their parenting experience. Regarding parents' coping, this involves meaning-making as a coping strategy, the use of symbolic resources and other practical coping strategies, such as learning and peer support. Finally, this study intends to suggest practical implications, respond to current limitations and set some future directions for research.

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Chapter 1: Introduction

This chapter introduces the research, by initially presenting the main topic and the aim of this study. I then present the historical context of disability world-widely and in Cyprus, starting from ancient history, reaching up to recent years. I continue by illustrating the macro-socio-cultural context of disability in Cyprus, that is, the prevalence of disability in Cyprus and the policies and services provided for people with disabilities, especially children, with developmental disabilities in Cyprus. I then discuss the micro-socio-cultural context, namely the Committee for the Protection of Persons with Intellectual Disabilities and the Early Childhood Intervention Coordinative Service (ECICS), where the participants of this study were selected from. I close this chapter with an overview of the study's chapters.

1.1. Main topic

Parents of children with disabilities face many difficulties and stressors, further and more complicated than the usual challenges of parenting. A child's diagnosis with developmental disability is an enormous change, a pivotal event that can be recorded as one of the most critical life experiences for a parent. Having a child with developmental disabilities carries a special meaning for the parent, who has to manage many changes in their life, their interpretation of the situation and their role as a parent. Current literature examines, on the one hand, disability in general, and developmental disability specifically, regarding how it is placed within the social context, analyzing the social aspects of disability. Stigma, inclusion and social care have been studied, emphasizing how each factor affects parents of children with developmental disability. On the other hand, there is a focus on emotional reactions, psychological coping and acceptance – or not – of disability in the immediate environment where it is experienced, namely how parents respond to this crucial for their life event.

The topic of this research is about the subjective meaning of parents raising their children with developmental disabilities, considering the complexity and quality of their experience. However, disability is a dynamic life-processing condition and cannot be approached without taking into consideration the context in which it takes place. In other words, I am interested to explore parents' experience on their children's developmental disability as a socio-culturally contextualized process.

1.2. Personal interest and motivation

My interest in studying the experience of parents' raising children with developmental disabilities was formed the last 14 years, during my work as a counsellor in the Early Childhood Intervention Coordinative Service.

Following my studies in the field psychology and psychotherapy, I started working as a counselor in the Early Childhood Intervention Coordinative Service. I have always detected the parents' distress and worries, who are trying to parent their children with all the developmental challenges they present in a social environment almost unfriendly towards them, in terms of services, benefits, access and inclusion. I have felt respect towards their struggle and at the same time angry due to the unfair treatment towards them, as second-class persons. However, beyond the practical issues of their experience, I have always had questions about how parents perceive and process their children's developmental disabilities, how they provide meaning to the experience and how they cope with the challenges that parenting poses within this specific social context.

Eventually, the first thoughts about this research project emerged, while listening to the parents' narratives during my work with them. How do parents raise a child who doesn't speak and they don't know how the child feels? How do parents feel when their child is different from the rest? How does the parent live and raise their children with disabilities within the particular social context, with the prevailing social stigma? How does a parent experience raising a child with disability? What does it mean to them? These questions, in combination with the parents' stories, were the motivation to study the experience of parents systematically, scientifically and in depth.

1.3. The aim of this study

What does it mean to raise a child with a developmental disability in Cyprus? How do parents make sense and how do they negotiate their parenting experience within the specific socio-cultural context? Up to present, disability remains a single problem of a single family (Talbot et al, 2010). The perception of disability as a personal tragedy is still powerful and disability is mainly represented as an individual problem (Albrecht, 2006). Despite the theoretical abandonment of the medical model (see chapter 2.1.1.), disability is largely approached in terms of normal and non-normal (McLaughlin et al, 2008). This places the emphasis on coping with disability, which is obvious and prevalent, instead of approaching the experience of disability, that is how parents receive, interpret and process this parenting experience. Family is constrained with a big deal of ongoing problems to manage on their own, including therapies, education and coping with everyday problems. Concerning parents specifically, the focus of the literature is on their emotional reactions, parental stress and caring styles of their children with disabilities (see chapters 2.2.1. & 2.2.2.). Regarding aspects of the social context, existing research deals with perceptions, social dynamics and stigma towards parents and children with developmental disorders (see chapters 2.2.3). In other words, disability is approached fragmentary and erratically, within several settings and regarding specific aspects, without taking into consideration how the above-mentioned issues influence or are influenced by the parents' understanding on their experience.

This is where the aim of this research study is identified. Disability needs to be approached as an experience, embedded in the social context where it takes place. This study intends to bring together the psychological aspects of parenting a child with developmental disability along with its socio-cultural implications for parents raising their children with developmental disabilities. In other words, this research aims to examine parents' experiencing their children's developmental disabilities "from the inside out", with the ultimate objective of utterly understanding parents' meaning on their children's developmental disabilities. Disability is not parents' single problem neither a one-dimensional phenomenon. Further, the rupture and the transition following disability (discussed in chapter 3) creates challenges in terms of parents' self-issues, which remain to be explored.

Overall, this research aims to explore the parents' meaning on their children's developmental disability in a socio-cultural approach, that is to explore the parents' experience as a socially-situated, cultural and psychological phenomenon. Particularly, this research aims a) to study how parents experience their children's developmental disability, in terms of the main milestones of the parenting experience, namely the parents' experience of the diagnosis, the parents' interpretation of the diagnosis and the social dimensions of the diagnosis, b) to explore whether parents engage in any meaning-making process about their children's developmental disabilities, and if so what it is and c) to examine the coping mechanisms that parents use in order to respond to the challenges of their parenting experience.

1.4. Selected terminology

According to DSM-V (American Psychiatric Association, 2013) developmental disabilities refer to a diverse group of conditions that affect an individual's cognitive, physical, social and/or emotional development. These disabilities typically manifest during the developmental period, including infancy, childhood and adolescence. Developmental disabilities can impact various aspects of daily functioning, including learning, communication, mobility, self-care, independent living and social interactions. The severity and nature of these disabilities can vary widely, and individuals with developmental disabilities may require additional support, therapies and accommodations to participate fully in everyday life. Developmental disabilities can be detected early in life and persist throughout an individuals' lifespan. Examples of developmental disabilities include intellectual disabilities, autism spectrum disorder, cerebral palsy and genetic conditions, such as syndromes (Down, Fragile-X or other). The most common developmental disabilities are intellectual disabilities, cerebral palsy and autism spectrum disorder (Henley et al, 2010).

In this research project, I use the term developmental disability or people/persons/children with developmental disabilities, which I choose for several reasons. Primarily, the term describes adequately the population under study, which is parents of children diagnosed with intellectual disability, autism spectrum disorder, cerebral palsy, syndromes or else, while emphasizing the age factor, with onset during the developmental period.

Furthermore, I choose the term developmental disability as consistent with the social model of disability (discussed in chapter 2.1.1). Other terms, such as 'mental retardation', have been already abandoned or are under an attempt to be replaced because they are considered outdated and in line with the medical model of disability (chapter 2.1.1). The social model of disability approaches disability as a social construct (Case, 2001), without, though, rejecting or ignoring terms such as disability or impairment but giving emphasis on how these terms are used. Developmental disability is, thus, selected as a non-stigmatising term, avoiding to attribute any negative status to people with disabilities (i.e. retarded). For the same reason, I also use person-first language, which puts the person before its diagnosis (i.e. person with autism), describing what condition a person has, rather than asserting what a person is (autistic), emphasizing that the condition does not define the individual (Botha et al, 2021). Terminology consistent with the social model contributes to reducing stigmatising representations associated with disability, shifting the focus from a deficit-based view to the one that recognizes the need for inclusion and accessibility. Besides, this use of terms highlights that people with disabilities are people with particular characteristics (Barton, 2009), without trying to maximize or minimize the condition of disability.

Additionally, consistent terms with the social model of disability are empowering towards the parents of children with disabilities, emphasising that disability is not only an individual's condition but is also shaped by cultural representations and social factors – or social barriers – impacting profoundly on the parents' experience. Further, this use of language helps improve the communication and understanding between people with disabilities, their parents and the broader community, in terms of understanding their experience and the difficulties they face. Lastly, with the term developmental disability, I attempt to prevent any negative conceptualization for people with disabilities (i.e. pathetic or disgraceful) and limit possible biases towards parents' experience of raising a child with developmental disability.

Lastly, the social model of disability aligns with a human rights approach, focusing on the rights of people with disabilities. Consistent terminology enhances efforts to ensure that their rights are respected, protected and fulfilled. Using terms consistent with the social model can contribute to a more comprehensive understanding of disability issues, revealing the social dimensions of disability.

1.5. The historical context of disability

Disability refers to a multidimensional and complicated concept (Albrecht et al, 2001). The description of disability as a phenomenon is culturally and time dependent (Whitaker, 2013). The historical context of disability reveals how the practices and the discourse around disability were understood and what they represented from time to time. In this brief historical overview, I go through the significant historical milestones in the field of disability, focusing mainly on the part of intellectual disability.

1.5.1. Distant history of disability (ancient years to 20th century)

In Ancient Greece, intellectual ability was of great value for citizens. Those not able enough were considered burdens and excluded from participation in civil society. Plato and Aristotle praised the ability to reason and differentiated people without this ability as socially inferior, missing legal status and barely humans (Stainton & Stainton, 2001). In the Homer's Epics, several terms are used to indicate intellectual disability, such as 'ánous' (άνους) meaning 'mindless' and 'aesifron' (αεσήφρων) meaning 'damaged in mind' or 'spiritually retarded'. The perception of the era suggested that the children born with a disability or a problem were a negative message or the anger of the gods (Patsis, 1977; Albrecht et al, 2001). In Sparta, the law indicated an early form of eugenics, where children with intellectual or other disabilities were left to die in the gorge Keadas of mountain Taygete, as they were considered useless according to the ideal warrior standard and they would possibly inherit their impairments to their children (Stasinos, 1991). The practice of abandonment or infanticide was common generally in Ancient Greece and Rome also for economic reasons as there were too many children and limited financial resources for many families (Albrecht et al, 2001). However, in Athens there was a special law 'for the weak' protecting and providing financial support to people with low income and unable to work due to their disability. The assessment of their support was authorized by the city's council (Edwards, 1997). In the Roman Empire, people with intellectual disabilities were often maintained by wealthy men for entertainment purposes, action that was considered good luck (Albrecht et al, 2001).

During Middle Ages in Europe, people with intellectual or other disabilities were considered to be possessed by demons. Isolation, torture, prosecution and execution were common practices (Russell, 1997). In the Medieval England, the property of 'idiots' would pass to the Crown according to the law of 'Prerogativa Regis' (Whitaker, 2013; Digby & Wright, 2002). The law's purpose was to provide protection of the person's property from exploitation but also to ensure their minimum living cost (Digby & Wright, 2002). During that time, intellectual disability was described using the terms 'natural fools' and 'idiots' (Digby & Wright, 2002), differentiating mental disability as 'lunacy' or 'non compos mentis' meaning 'not master of one's own mind' (Neugebauer, 2002; Digby & Wright, 2002). The word 'natural' indicated difficulties from birth and the word 'fools' demonstrated the delay in intellectual development without ever reaching an adult level of intellectual capacity. Both terms refer to people who are congenitally disabled with permanent difficulties (Digby & Wright, 2002). In terms of inclusion of people with intellectual disabilities, the lack of education and the primitivism of the era made people with mild or moderate intellectual disabilities represented as not that different (Metzler, 2016). Additionally, the great poverty level of that time – resulting to malnutrition, infectious diseases and increase of impairments –and the acceptance of the poor as natural part of the society (begging was not stigmatised) led to parallel acceptance of people with disabilities as a subgroup of poor people (Albrecht et al, 2001).

From the 14th until the 18th century, the ideas of humanism and enlightenment influenced all aspects of public life and moved the focus on the physiological and anatomical study of the body (Albrecht et al, 2001). Intellectual disability was then considered a disease (Digby & Wright, 2002) rather than an unexplained supernatural phenomenon. The emphasis turned to education and treatment of people with intellectual disabilities rather than to protective care by family or monasteries as used to be until then (Tsakanikos & McCarthy, 2014). A typical example of the trend of that time was the effort of French Jean Itard, who managed to educate a child with mutism and severe intellectual disability (Tsakanikos & McCarthy, 2014). Institutions and asylums provided basic care and a minimum education but also confined people with intellectual disabilities (Porter & Wright, 2003; Whitaker, 2013). The terms used to describe intellectual disability depict this emphasis on pathology. ‘Idiots’ and ‘idiocy’ were still used, as did Edward Seguin – a student of Itard, trained in medicine who opened a school for the education of people with intellectual disabilities (Barr, 1995) – in order to present his individualized treatment program (Tsakanikos & McCarthy, 2014). Howe (1848) introduced the term ‘simpleton’, meaning a person with limited learning skills lacking in what was considered as ordinary sense or intelligence (Metzler, 2016; Gopalan, 2016). The terms ‘idiot’, ‘imbecile’ and ‘feeble-minded’ were also systematically used by British census, as a separate factor, to record people with intellectual disabilities (Porter & Wright, 2003). At the beginning of the 20th century, Henry Goddard – a main figure in the eugenics movement who spread the use of the Binet scale in America (Albrecht et al, 2001) – introduced a first measurement of intellectual disability, with his suggested term ‘moron’ (‘feeble-minded’ at first) for the adult with the intellectual skills of a school-age child (mild), ‘imbecile’ (moderate) for the adult considered as less able to reason and ‘idiot’ (severe) for the adult described as in the lowest end of the ranking, below ‘imbecile’ (Whitaker, 2013; Albrecht et al, 2001). Goddard was inspired by Alfred Binnet’s scale, who introduced the first intelligence test in France and marked the beginning of quantifying intellectual capacity (Albrecht et al, 2001; Whitaker, 2013). The French government had, at that time, legislated universal education for children with and without intellectual disabilities, placing the later in special education than in asylums (Nicolas et al, 2013).

An important milestone in the history of approaching intellectual disability was the eugenics movement which appeared at the end of the 19th and the beginning of the 20th century. During that period of time, the theory of Social Darwinism was largely accepted and embraced by a broad part of society, including distinguished biologists, researchers, physicians and politicians. Social Darwinism was based on the idea that the process of human evolution is done through natural selection (Hofstadter, 1992). Based on the work of Huxley (1881) and Fischer (1877) about hereditary explanations, Francis Galton, the founder of eugenics, supported that intellectual ability was inherited and that societies, through reproductive planning, should try to improve their population’s genetic material (Whitaker, 2013). In this context, disability was approached as a threat to the white race and intellectual disability as a form of exceptional regression. The terms used to describe intellectual disability was ‘slow’, ‘retarted’, ‘feeble-minded’ or ‘of arrested development’

(Adams et al, 2015). Poverty was an important complementary factor, believed to be the result of natural inferiority, which should be eradicated from human population and not overcome through governmental aid to the poor (Spencer, 1884). The ideas of protecting the 'normal' from the 'non-normal' and promoting white supremacism triggered extreme and cruel practices like sterilization and segregation (Lombardo, 2011; Adams et al, 2015). Between 1930 and 1940 massive sterilization of thousands of people with intellectual disabilities in some US States and Central European countries took place (Sofair & Kaldjian, 2000). In 1942, the American Psychiatric Association supported officially the euthanasia of children classified by APA as 'idiots' and 'imbeciles' (Albrecht, 2006). Eugenics were enormously applied by the Nazis, period in which thousands of people with mental or intellectual disabilities were killed in groups (Seeman, 2005).

During the same period, John Langdon Down described, from an anthropological perspective, the external appearance and other traits of people with what we now call trisomy 21 or Down Syndrome. He used the term 'Mongolian imbecility' or 'Mongolian idiocy' because of the similarities he noticed with certain Asiatic populations. 'Mongolism' for Down and other researchers represented a regression to earlier stages of human evolutionary development. His research paid great emphasis to 'normality' and described how people with intellectual disabilities differed from what was considered as 'normal' (Crookshank, 1924; Albrecht, 2006). The term became widely used and the 1967 Ciba Symposium of the disorder had the title 'Mongolism' (Beighton & Beighton, 1986). In 1961 a group of respected scientists demanded the abandonment of the term because of its 'misleading connotations' and the embarrassment that the term may cause to Asian scientists or symposium participants. They suggested instead the terms 'Langdon Down Anomaly', 'Down's Syndrome or Anomaly' or 'Congenital Acromicria'. The term 'Mongolism' was finally abandoned by WHO after the relevant request of the Mongolian People's Republic (Howard-Jones, 1979).

From 1960 and onwards, the term mostly used to describe intellectual disability was 'mental retardation', meaning a delayed intellectual ability. The severity was distinguished as mild, moderate or severe. 'Mental retardation' was the term adopted in late '80s by the American Association on Mental Retardation (before American Association on Mental Deficiency and now American Association on Intellectual and Developmental Disabilities). The previous version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) also used the term 'mental retardation' to define the 'significantly sub-average intellectual functioning' (American Psychiatric Association, 1994). The term is widely used even today, being, according to WHO, the most used term between several countries around the world (World Health Organization, 2007).

The practices used at these various time points in Cyprus towards people with intellectual disabilities did not differ much from the above mentioned European and American context. In the 19^{th} century Anglo-colonial Cyprus, a rural society where prejudice and fear prevailed, there were reports of burning infants who were severely different than the norm (Ftiaka, 2000). The ‘insanes’ (‘frenovlavis’, meaning damaged in mind), referring to both people with intellectual and mental problems, were kept in asylums, where isolation and not therapeutic measures was the main objective (Georgiades, 1995). Apart from ‘insanity’, other various terms have been historically used in greek-speaking countries, including Cyprus, such as ‘idiocy’, ‘oligofrenity’, ‘cretinism’ or ‘intellectual insufficiency’ (Kakouros & Maniadaki, 2003). The most predominant term, used until lately, was the term ‘intellectual retardation’, meaning the intellectual delay of development. The official translations of diagnostic manuals DSM-IV and ICD-10 also used that term. Some researchers considered the term ‘intellectual inferiority’ better, as it denotes that their intellectual development is not only delayed – as with ‘intellectual retardation’ – but also incomplete (Kakouros & Maniadaki, 2003). In Cyprus, the term ‘intellectual retardation’ was used until recently in the same way it was defined in the first official definition ‘on Intellectually Retarded Persons Law 117/89’, meaning “any person of any age who is permanently incapable of ensuring by himself/herself all or some of the necessary needs for a normal personal or social well-being due to lack of development or inadequacy, whether congenital or not, of his/her intellectual functioning” (Official Gazette of the Republic of Cyprus, 1989, p. 1). This definition represents people with intellectual disabilities as unable or deficient, totally determined by their condition and holding a disadvantageous position.

The above-mentioned definitions and practices depict the medical model of disability. Historically, the medical model consisted the dominant discourse concerning disability for decades and was prevalent until the 1980s (Albrecht et al, 2001). The medical model approaches disability as an individual problem (Albrecht, 2006), as a tragic problem of an unfortunate individual (Oliver & Barnes, 2000), who is identified by their disability or their physical condition (further discussed in chapter 2.1.1). To position the medical model historically we need to go back to the Cartesian question of the separation of mind and body, described as Disability theory and later expanded into an entire field of research, namely body and society. Social differences and problems of social support created the social need to develop disability definitions and methods of assessment and understanding disability. This resulted in disability definitions based on physical problems as depicted in the medical model, and afterwards to social models of disability, environmental and genetic models and other modern political economic theories of welfare (Albrecht et al,2001).

1.5.2. Recent history of disability (20th century to present)

The end of the Second World War and the defeat of totalitarian regimes created the need to protect human rights on an international level. A very first attempt of human rights equation between people with and without disabilities was accomplished in 1948 with the Universal Declaration of Human Rights. The Declaration was signed by the United Nations General Assembly and was then adopted by numerous states all over the world. It included separate articles referring to healthcare rights and a standard of living for everyone, including those with physical impairment (United Nations, 1948). The Declaration of Human Rights emphasized for the first time on the basis of equality that people with intellectual disabilities “remain ontologically people” as anybody else and not considered, officially at least, “belonging to an inferior group of people” (Anstotz, 1997, p. 41). Although an important step in the recognition of the rights of people with intellectual disabilities, it nevertheless reveals the predominant stigmatization of that time around disability issues.

From 1950 onwards, several small milestones started to denote changes for the life of people with intellectual disabilities, revealing a change of attitudes towards them. The beginning of deinstitutionalization indicated the turn to more community-based treatment approaches (Wright, 1997). Still people with intellectual, psychiatric or other conditions were confined together in settings with no exact purpose or with no expectations to get better (Mansell & Ericsson, 1996). The advent of certain medicines, like the antipsychotics or penicillin, was highly related to the attempt of deinstitutionalization (Albrecht et al., 2001). Additionally, several incidents of abuse inside institutions but also an attempt to limit costs were considered to have played an important role to this change (Whitaker, 2013). Deinstitutionalization’s main objective was the treatment and respect for people suffering from several conditions, quitting the punishment philosophy which was central until then. In 1961, President Kennedy in USA assigned to the "President's Panel on Mental Retardation" to search solutions and make recommendations for the problems of people with intellectual disabilities. Their 95 recommendations included decrease of the number of institutions, increase of community-based services and the need for scientific research. In the next 20 years, the population of large US institutions for people with intellectual disabilities decreased by 67.3% (Lakin et al, 1996). The emphasis was given in the civil rights of people with intellectual disabilities based on the concept of what was then considered ‘normalization’ (Albrecht et al, 2001).

The idea of ‘normalization’ was introduced by Wolfensberger (1972), supporting that people with intellectual or other disabilities should not be regarded as objects or ‘ludicrous’ but as equivalent and valued members of society. In order to fulfill this role, services should help these people to live in the same environment, like anyone else, and to participate in any activity of daily life. Having typical life experiences and acquiring socially useful roles would help them get included and facilitate the contact between people with and without disabilities and the reduction of prejudice, fear and discrimination towards them. The concept of ‘normalization’ recognized substantially the social role of people with intellectual disabilities, the so called ‘social role valorization’ (Wolfensberger, 1991). ‘Normalization’ brought a big change in disability’s conceptualization, namely that disability was not considered anymore a medical problem of an unfortunate individual but a social issue. This can be considered a first attempt to situate people with intellectual disabilities within the social context. However, that was not a totally new shift, since Ellis as early as 1963 was presenting ‘mental retardation’ as a social problem (Emerson et al, 2004).

The change of approach towards disability and the increased disability activism started signifying a different line in legislation. In 1970, the UK ‘Chronically Sick and Disabled Person’s Act’ introduced policies for people with disability regarding their accessibility to equal opportunities and to community-based services. The Act covered issues of housing, education and public buildings (Topliss & Gould, 1981). In 1973, the USA ‘Rehabilitation Act’ (Section 504) prohibited the discrimination against people with disabilities in any programme funded by the government (Barnes, 2011). At an international level, the UN defined the change with the ‘Declaration on the Rights of Mentally Retarded Persons’ in 1971, followed by the ‘Declaration on the Rights of Disabled Persons’ in 1975. The United Nations Declarations emphasized the equality of fundamental rights between people with and without disabilities (United Nations, 1971; United Nations, 1975): “the mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings” (United Nations, 1971, article 1).

The ‘70s were a decade clearly marked by the activism of several minority groups, like the women’s movement, the civil rights movement for the rights of African Americans and other ethnic minorities and the homosexual liberation movement. Those movements raised motivation and were finally associated with the deinstitutionalization and the disability rights movement (Whitaker, 2013). The disability rights movement initially included a group of blind and deaf people in the United States, United Kingdom and Ireland who were organized and activated, asking social, educational and economic rights (Adams et al, 2015). During the same decade, the ‘Independent Living Movement’ emerged in several countries, which claimed that people with disabilities should have control of their own lives, including decisions about where to live, with whom to live, etc. The primary social and cultural representation of people with disabilities as passive and dependent collapsed by the main objective of the ‘Independent Living Movement’ towards their self-determination (Watson et al, 2012). Disability activism in the UK was also expressed through the establishment of the ‘Union of the Physically Impaired Against Segregation – UPIAS’, with its initial goal being to fight segregation and confinement of people with disabilities in hospitals and care settings. However, quite soon UPIAS turned out to emphasize the social nature of disability and how society disables people with physical or other impairments (Albrecht, 2006).

In 1976 disability and impairment are clearly distinguished for the first time by UPIAS. With the term impairment they denoted any kind of dysfunction of the body, whether it is lack of a limb, a defect or an intellectual disorder. Disability, on the other hand, was used to refer to the societal exclusion of individuals with impairments (Union of the Physically Impaired Against Segregation, 1976). This distinction was rapidly spread and adopted by health and care professionals, service providers, associations and parents. In terms of definition, UPIAS created a critical turning point to the way intellectual disability was since defined: “disability is the disadvantage of restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” (Union of the Physically Impaired Against Segregation, 1976, p. 14). This definition exercised considerable influence towards a more social approach of disability and was gradually adopted by national and international organizations (Watson et al, 2012).

Regarding the definition of intellectual disability, the term ‘mental retardation’ introduced by the American Association on Mental Retardation (AMMR) was still in use but revised so as to include the concept of adaptive behaviour. “Adaptive behaviour is the effectiveness or degree with which the individual meets the standards of personal independence and social responsibility expected of his or her age group” (American Association on Mental Deficiency, 1983, p. 157). This input placed the definition of intellectual disability on a more social context. Even later revisions of the AMMR definition (Schalock et al, 2002), emphasized on the importance of adaptive functioning but placing intellectual limitations and adaptive behaviour on an equal basis. According to Harris & Greenspan (2016) ‘mental retardation’ is a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. Interestingly enough, the definition of the American Association on Mental Retardation used the same term ‘mental retardation’ but with a different meaning, not ascribing disability to the person but giving emphasis to the diagnosis. This is much related to the prevailing use of the term disability, introduced mainly by WHO but also consists a clear proof that words are reconstructed by the dominant disability model, which at time was the social model (discussed in chapter 2.1.1). The AAMR definition proved to be a quite influential definition as it was, and still is in some countries, the definition most often used (European Intellectual Disability Research Network, 2003). The American Association on Mental Retardation (formerly ‘Mental Deficiency’) was renamed as American Association on Intellectual and Developmental Disabilities in 2007[1], matching the present social approach on intellectual disability.

From 1980 onwards, the World Health Organization attempted to provide universal definitions and to classify disability. The International Classification of Impairments, Disabilities and Handicaps – ICIDH was introduced in order to complement the WHO's International Classification of Disease, which categorized impairments, disabilities and handicaps and defined intellectual disability on the basis of IQ measurements (World Health Organization, 1980). ICIDH distinguished the 3 concepts – impairment, disability and handicap – and defined them in terms of loss, restriction or disadvantage compared to what is considered normal (Watson et al, 2012). In 2002, the International Classification of Functioning, Disability and Health (ICF) was issued in order to replace the ICIDH, focusing on health instead of impairment and on functionality instead of disability (World Health Organization, 2002). The central point of assessment for ICF is what a person can instead of what a person cannot do. Specifically, the ICF codifies the person's physical functions instead of disability, the activity of the individual instead of the limitation of activity and participation instead of isolation, offering a new biopsychosocial dimension on the assessment of disability. However, the ICF was criticized about being a quantitative tool which classifies human abilities on the 'ruler of health and disability' and therefore emphasizing impairment, despite the adoption of social terms around disability (Symeonidou, 2014). ICIDH and ICF were also criticized as proposing universal definitions of disability, reflecting a realist conception of impairment, where disability is an umbrella term for impairment, activity limitations and participation restrictions, separating though the body and society – thus impairment and disability – meaning that they fail to include the reality of the body and the disability experience (Goodley & Runswick-Cole, 2013).

In 2010, the European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families (World Health Organization, 2010[2]) defined intellectual disability as a "significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which started before adulthood, and has a lasting effect on development. Disability depends not only on a child's health conditions or impairments but also and crucially on the extent to which environmental factors support the child's full participation and inclusion in society". Even though the WHO definitions focus on the concept of 'normalcy' and 'able-bodiness' (impairments), however

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[1] https://www.aaidd.org/about-aaidd

[2] https://www.who.int/southeastasia/health-topics/mental-health/key-terms-and-definitions-in-mental-health#intellectual

they denote a turn into the way disability is approached, including social and environmental factors as well.

In 2006, the Convention of the Rights of People with Disabilities is adopted by United Nations and ratified by numerous countries. The Convention does not focus on disability or its causes but on human diversity, giving more emphasis on how to ensure persons with disabilities effective participation in society on an equal basis with others (United Nations, 2007). The emphasis is given on the person and not on disability, describing the rights of persons with disabilities and presenting disability as the result of the interaction between persons with disabilities and attitudinal and environmental barriers. The language used in the Convention is a person-first language, prioritizing persons and not disability, with the latter consisting a simple characteristic of the person. Person-first language, first appeared in the ‘80s, when activists demanded a less labeling form of language to denote this group of people (Albrecht, 2006). The person-first terminology places a linguistic distance between the individual and his/her condition (i.e. person with disability instead of disabled) (Adams et al, 2015). The rationale of this use of language is representing persons with disabilities as people first (Gabel, 2001) and their disability as a characteristic, among others, to their personhood (Albrecht, 2006). Person-first language has been criticized for being defensive and placing disability last and therefore denying its importance for the person (Albrecht, 2006). However, the language is critical in relation to disability issues, as it is not only a label for people with disabilities but it consensually captures the common meaning (Valsiner, 2014) encompassing the description of people with disabilities.

A broadly used term in order to describe people with intellectual disabilities, with an increasing frequency from 60s onwards, was ‘special needs’ (Gernsbacher et al, 2016). A person with ‘special needs’ represents somebody who requires specialized assistance to gain access to certain aspects of life, like education, transportation, work or other. In some countries, including Cyprus, the term has been related to special education needs and, therefore, to children population. The term seems to be preferred by parents of children with disabilities, instead of disability, whereas it seems to be rejected by disability advocates. Literature has described the term as inappropriate and patronizing, considering it a euphemism (Myers & Parker, 1996; Gernsbacher et al, 2016). In its core meaning, it is questionable how accurate the term is, as all people share similar basic needs and there is no exact way to define ‘special needs’ between them. The term ‘special needs’ distinguishes the persons from their needs and, consequently, their problem (person-first language), but focuses completely on what a person needs, namely his/her biological demands, referring inevitably to the separation between ‘normal’ and ‘special needs'. It is a term directly referring to the traditional dominant dipole of ability and inability (Watson et al, 2012).

More recently, the term ableism is used to describe the discrimination against people with disabilities (Albrecht, 2006). Ableism includes any belief, attitude or behaviour towards persons with disabilities as being less worth of respect or appreciation, less able to contribute and participate or have limited inherent values than people without disabilities. This discrimination because of their disability may be conscious or unconscious, may be integrated into institutions or practices, into care or educational systems or the broader culture of a society. Ableism may limit the skill's development of people with disabilities and reduce their inclusion into their communities (Campbell, 2009). The concept of ableism is based on the ungrounded separation of what is considered as 'normal' and 'non-normal', of perfection and faultiness, questioning the idea of 'normalcy' and health in several contexts and in relation to other concepts, such as sexuality, gender, race or more (Adams et al, 2015). Goodley (2014) relate ableism with the neoliberal context, where concepts such as flexibility, achievement and success are of additional value, with ableism resulting in the exclusion of people due to cultural norms associated with self-sufficiency, autonomy and independence (Goodley et al, 2019).

In the Cypriot context, the approach of intellectual disability has been following the international course of movement on a slower pace. The first attempt towards an organized group of people with disabilities is the establishment of Cyprus Confederation of Organizations of the Disabled (CCOD[3]) in 1984, with their main goal to protect and promote the rights of people with disabilities in Cyprus. KYSOA is an umbrella-organization, standing for 8 Pancyprian Associations of people with disabilities and generally representing people with disabilities in Cyprus. Additionally, it is the official social partner of the Government in decision and legislation making concerning any issue which relates directly or indirectly to people with disabilities. The organization is based on the values of self-representation of people with disabilities, of participation, of solidarity and of social partnership, which consist a certain progress in the local social milieu.

In 1989, the Committee for the Protection of Intellectually Retarded Persons was established according to the Law on Intellectual Retarded Persons 117/89 (Official Gazette of the Republic of Cyprus, 1989), aiming to safeguard and claim the rights of persons with intellectual disabilities. The Committee was the body responsible for inspecting, reviewing, defending and promoting the rights of people with intellectual disabilities in Cyprus, while the government is responsible to legislate in order to reserve those rights. Cyprus is among the few countries with a distinct Law for people with intellectual disabilities. This legislation was amended in 2018 by implementing the change in terminology and adopting the title of

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[3] www.kysoa.org.cy

the Committee for the Protection of Persons with Intellectual Disabilities. However, this Law does not still provide the direct participation and representation of people with intellectual disabilities, since the Committee's members are parents of people with intellectual disabilities and state members (Official Gazette of the Republic of Cyprus, 2018).

From 1990 onwards, important legislations have demonstrated a change of approaching disability in Cyprus. In 1999, the Law for the Education of Children with Special Needs 113(I)/99 provided the detection, assessment and provision of inclusive special education courses for students within the school setting (Official Gazette of the Republic of Cyprus, 1999). However, the special classes in schools as a measure of inclusive education have been considered segregative, dividing 'special' students and teachers from the rest of the school (Angelides, 2004). In 2000, the Law for people with disabilities 127(I)/2000 officially recognizes the rights of people with disabilities in several aspects of their life on the basis of the European ideas of non-discrimination and reasonable adjustments for people with disabilities (Official Gazette of the Republic of Cyprus, 2000).

A great step regarding disability issues in Cyprus was made with the ratification of the UN Convention of the Rights of Persons with Disabilities. The Convention provides a detailed list of rights for people with disabilities that should be ensured by the state, including non-discrimination, participation, accessibility, education, health, work, respect, equality on opportunities and more (Official Gazette of the Republic of Cyprus, 2011). Despite law advancement though, people with disabilities in Cyprus continue to face significant problems in many aspects of their lives (social, working, educational, political, caring and more), which they are required to deal on their own or within their families (Committee for the Protection of Persons with Intellectual Disabilities, 2023). Hence, the social pace of change and the real integration of people with disabilities in Cyprus is not consistent with the official legislative progress of the State.

Regarding definitions, the Cyprus Confederation of Organizations of the Disabled (CCOD) uses the term disability, denoting a social approach to disability. However, in oral language people with or without disabilities relate the term disability with someone with moving difficulties (Symeonidou, 2009). The term 'special needs' is broadly used for in lay and institutional discourse. While the term 'special needs' does not represent a legal term and is not used in Acts worldwide (Gernsbacher et al, 2016), in Cyprus it is used as a term to signify children with special educational needs in schools. According to the Law for the Education of Children with Special Needs 113(I)/99, a "child with special needs" means "a child with severe learning or special learning, functional or adaptive difficulty, due to physical, intellectual or other cognitive or mental deficiencies and who have been assessed as in need of special education and training" (Official Gazette of the Republic of Cyprus, 1999). The term has been also used by several charities and has been related in common speech with disability, reinforcing a sense of pity and alms around disability (Peters et al, 2009).

Subsequent laws used the term disability and also introduced a broader description to what this term means. The current official State definition refers to disability as ‘any form of inadequacy or disadvantage that causes a permanent or of indefinite duration physical, intellectual or mental limitation to the person who, taking into account the medical background and other personal data of the individual, substantially reduces or excludes the possibility of performing one or more activities or functions that are considered normal and essential to the quality of life of any person of the same age who does not have such an insufficiency or disadvantage’ (Official Gazette of the Republic of Cyprus, 2000). The definition separates disability from the person and describes disability in a comparative way and not as a person’ s problem. However, the definition does not include the limitations related to external factors like structural constraints, referring only to limitations caused by the person (Dimitriou, 2014). Interestingly, a subsequent legislation on Public Benefits and Services, used the same verbal description to define the person with disability, adding the cause of his/her disability, which can be congenital or acquired (Official Gazette of the Republic of Cyprus, 2006). This confirms the absence of a unified policy regarding disability but also the weakness of legislators to fully understand the separation between impairment and disability. Potentially, this inconsistency also partially explains the way disability is represented in Cypriot society, as mentioned above. The Convention of the Rights of People with Disabilities consists the last official definition opposed to this long-established approach of disability, following a social approach, presenting disability as part of human diversity and emphasizing the rights of people with disabilities (Official Gazette of the Republic of Cyprus, 2011).

The above-mentioned transitions in disability area marked the beginning of the diffusion of the social model of disability. According to the social model, disability is a social construct (Case, 2001), which is determined by the limitation of an individual’s opportunities to the life of his/her community on an equal basis with others, due to physical and social barriers. The social model of disability is further discussed in chapter 2.1.1.

The history of terminology around disability and the repeated changes of the terms used indicate the deep-rooted representation of disability within the social context, as a problem and as an unwanted condition, with the persons with disability being undervalued and without a right to self-definition. It took many changes in terminology and many decades for social processes to evolve and allow a broader understanding of disability as a social and cultural construct.

1.6. The macro-socio-cultural context of disability in Cyprus

1.6.1. Disability in Cyprus

In Cyprus, disability prevalence is not clearly defined, since there are no exact figures for all people with disabilities by age and disability. The Cyprus Statistical Service collects data on disability only in the context of other surveys and censuses like health surveys. Additionally, relevant state departments – such as the Mental Health Services of the Ministry of Health, the Special Education Section of the Ministry of Education & Culture or the Department of Social Inclusion of People with Disabilities – maintain separate data which refers only to the population they serve. According to the European Council[4], 19,2% of Cyprus population over the age of 16 had some form of disability in 2022.

Regarding intellectual disabilities, 2754 people with intellectual disabilities of any age have been registered in the registry of the Committee for the Protection of Persons with Intellectual Disabilities in December 2022. The registry does not include all population with intellectual disability in Cyprus but people who themselves or their parents voluntarily have approached the Committee and have given their consent to get registered, according to the 117/2018 Law on Intellectual Retarded Persons (Committee for the Protection of Persons with Intellectual Disabilities, 2023). From them, 33% presents moderate intellectual disability, 39% mild and 22% severe. Only 2% of people registered have been married, 87% of them is living with their parents and/or siblings and 3% live on their own.

Children population with disability is similarly unclear in Cyprus. According to the definition used in the Law for the Education of Children with Special Needs 113(I)/99, students with 'special needs' (term explained in chapter 1.5.2.) may attend a mainstream class, a special class – which is included in the mainstream school – or a special school. During the 2020-2021 school year, 6836 children with 'special needs' attended public kindergartens and elementary schools, of which 657 attended 116 special classes (named as special units). These students follow individual curriculum, in which special education and speech therapy classes are included. Special education is also provided in Special Schools for children with multiple and severe disabilities. The same school year, 498 students attended the 9 special schools in Cyprus. The school of blinds and the school of deaf are also considered as Special Schools. The Ministry of Education employs special educators of any specialty for the special schools, including teachers of specialized learning, teachers of intellectual, functional and adaptive difficulties, teachers for deaf and blind students, special gymnastics teachers,

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[4] https://www.consilium.europa.eu/

music therapists, occupational therapists, speech therapists, educational psychologists and physiotherapists. The Educational Psychology Service of Ministry of Education & Culture is responsible for assessing and offering interventions and other programs for students with mental, learning and adaptive problems. During the same school year, the Educational Psychology Service had 7789 intakes of students of all ages, 12,8% of which concerned preliminary education students while 48,4 % primary education students (Ministry of Education, Culture, Sports and Youth, 2022).

In the year 2022, 186 families with children with developmental disabilities of preschool age asked support and guidance from the Early Childhood Intervention Coordinative Service of the Committee for the Protection of Persons with Intellectual Disabilities (Committee for the Protection of Persons with Intellectual Disabilities, 2023). However, the above-mentioned data concern the cases that were referred to these services and not the exact number of children with developmental disabilities in Cyprus.

1.6.2. Overview of services

Based on the legislation framework mentioned in the previous chapter, the services provided to people with intellectual and/or developmental difficulties in Cyprus are offered by the various Ministries. In this chapter I examine the services provided to people with intellectual disabilities, with a focus on childhood, by area of service, and I discuss various limitations about each of them.

1.6.2.1. Health services

In terms of health, services for children with intellectual disabilities are provided in the hospital departments, with Archbishop Makarios III Hospital being the reference point as the state hospital for children and mothers. There is the Genetics Clinic and the Pediatric Neurology clinic, where children with developmental disorders and/or intellectual disabilities are diagnosed, assessed and being followed up. These two clinics are offered only at the Makarios Hospital, that is only in Nicosia. In addition, services are provided by the Child & Adolescent Departments of the Mental Health Services – offering child psychiatrist, clinical psychologist and occupational therapist services – the physiotherapy departments and the speech therapy departments, in the respective specialties, departments which operate in most general hospitals of the big cities in Cyprus (Nicosia, Limassol, Larnaca, Paphos, Paralimni)[5].

Since 2019, health services are also provided through the General Health System (GHS) which operates based on relevant legislation (Official Gazette of the Republic of Cyprus, 2022). The GHS aims to provide universal access to health care services. The services are provided by professionals who operate privately and are registered with GHS, concerning outpatient care – which includes health care provided by the general practitioner or by a specialist doctor, laboratory tests and provision of medication – inpatient care, accident and emergency department, ambulance department and services of other health professionals – such as clinical psychology, clinical nutritionology, speech therapy, occupational therapy and physiotherapy. These services are provided with additional patient payment.

However, there are certain limitations regarding the provision of health services in Cyprus. With regards to children, there is no specific system of managing children with disorders or disabilities, that is no protocol or care path for children with disorders has been defined. Another problem is that a large number of children are not detectable by the state services, either during the detection or because the parents choose to turn to private practitioners. In addition, another limitation is about the availability of therapists, with occupational therapists, a critical specialty for children with developmental disabilities, not being available through the GHS (unless through specific GHS State Departments). Some GHS State Departments, though, do not employ sufficient staff, as a result of which long waiting lists have been created in certain specialties in only four years of operation. Another implication is that records are not systematically kept, resulting in having no official statistical data, for instance how many children with Down syndrome have been assessed or treated by GHS practitioners in Cyprus (Committee for the Protection of Persons with Intellectual Disabilities, 2023; Commissioner for Children's Rights in Cyprus, 2021).

Some other limitations concern the coverage of specific services, as the GHS offers a certain maximum number of sessions per diagnosis and in many cases the maximum number of sessions covered is very small, considering the needs of children with developmental disabilities. For example, the sessions provided by a Clinical Psychologist are only 6 for children with intellectual disorders and 12 for children with autism. Thus, in some cases, the number of sessions per year may cover one or two months of the needed therapy, placing a financial burden on the families of children with disabilities and increasing the risk of the child's developmental regression, when the family cannot afford the private sessions. Additionally, the GHS was designed with no focus on prevention, since in some specialties,

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[5] https://www.moh.gov.cy/

such as clinical psychologists, only severe psychopathology is covered (Committee for the Protection of Persons with Intellectual Disabilities, 2023; 2021; Commissioner for Children's Rights in Cyprus, 2021).

1.6.2.2. Education

Regarding education, special education to children with disabilities is provided in public schools in various forms according to the needs of each child. The most common form of education is full integration in the mainstream class along with individual support. The support concerns one-to-one special education and speech therapy classes to children attending mainstream school classes (primary or kindergarten) and the provision of a shared or a personal class assistant if approved. Special education can also be provided by attending a special class of a mainstream school, with partial integration in the mainstream class. The special classes (named as special units) operate in classes included in the mainstream schools, where special education and speech therapy are provided. Special education is also provided in special schools, where the ultimate goal is the re-integration of children into their natural environments, such as the mainstream schools and the community. Special education schools provide specialized special education courses to develop the child's skills and abilities to the maximum extent possible. Specifically, the specialties provided within the special school concern education for children with "special learning, intellectual, functional and adaptive difficulties, education for deaf and blind children, special gymnastics, music therapy, occupational therapy, speech therapy, audiology, educational psychology services and physiotherapy"[6]. There are nine special schools in the big cities throughout Cyprus. Finally, Special Education is also provided in other areas according to the needs such as in public hospitals in case of compulsory hospitalization of the child or home schooling, which is only approved in exceptional cases. The provision of any form of special education is assessed for approval by a multidisciplinary team of the Ministry of Education (Committee of Special Education), which usually includes an educational psychologist, a speech therapist, a special teacher and a general teacher (Official Gazette of the Republic of Cyprus, 1999-2001)[7].

However, there are some limitations regarding the education of children with disabilities. The age limit for entering the public schools is the age of three years whereas special education is not provided in private schools, leaving many children without special

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[6] https://www.moec.gov.cy/eidiki_ekpaidefsi/ekpaideftiko_voithitiko_prosopiko.html

[7] https://www.moec.gov.cy/eidiki_ekpaidefsi/nomothesia.html

education or assistant or not accepting the children to attend the private school without assistant. Regarding the approval of any form of special education within the public school, there are serious delays in the assessment process (up to 6 months), resulting in children not getting in time special education and, in some cases, not being accepted to attend the school without the approval of the relevant Committee. Another limitation concerns the access to specialized therapies, such as occupational or music therapy, which are provided only in special schools. This practice does not favour the stay of children with disabilities in mainstream schools, directing them to special schools because of the therapies provided (Committee for the Protection of Persons with Intellectual Disabilities, 2023; United Nations, 2017).

Another problem is that not all specialties are available at public schools, such as psychologists, to emotionally support children with developmental disabilities and their parents. Another significant limitation concerns the future of children with disabilities, since there are no organized centers or settings for young adults with disabilities after graduating school. Overall, the special education provided in public schools should serve the ultimate goal of the development of skills and the complete and effective integration of children with disabilities into society, namely the mainstream school, and their participation in the community. The special education provided in public schools as described above do not seem to serve this purpose (Committee for the Protection of Persons with Intellectual Disabilities, 2023; United Nations, 2017; Commissioner for Children's Rights in Cyprus, 2021).

1.6.2.3. Social welfare

In terms of social welfare, benefits and services related to adults and children with disabilities, they are provided by the three departments of the Deputy Ministry of Social Welfare – which are the Social Welfare Services, the Department for Social Inclusion of People with Disabilities and the Welfare Benefits Administration Service.

The Social Welfare Services aim to ensure the protection and care of vulnerable groups of the population, including people with disabilities. As part of their duties, the Services operate the Children Protection and Activity Centers, the Family Counselling and Support Services and the Community Work Program through which the community kindergartens are funded. These kindergartens are low cost and accept children younger than three years old. The Social Welfare Services also manage the State Grants Scheme, through which childcare programs for young children and care centers for adults with disabilities operate. These programs grant NGOs that operate at the local level, with 16 such centers operating in Cyprus for care, education and therapeutic interventions of children with developmental disabilities. These centers offer specialized therapies for children with developmental disabilities at low cost[8].

The Department for Social Inclusion of People with Disabilities (SID) is the official body of the state for the design, coordination, implementation and monitoring of policies for people with disabilities. The SID work is implemented with the help of the cooperating Ministries, and the competent social partner, the Cyprus Confederation of Organizations of the Disabled (CCOD). The actions of SID concern the preparation of the National Disability Action Plan, the implementation of the new Disability and Functionality Assessment System (discussed in chapter 1.3.2.), the creation of a National Register of People with Disabilities and the implementation of the UN Convention on the Rights of Persons with Disabilities across Cyprus. The SID is also responsible for the Social Benefit Schemes, including benefits such as severe physical disability allowance, quadriplegic carer's allowance, blind sponsorship, financial assistance scheme for the supply of wheelchairs and more. Lastly, the SID deals with the vocational training and employment of adults with disabilities[9].

The Welfare Benefits Administration Service (WBAS) is responsible for providing benefits to various population groups, including people with disabilities. The basic allowance for adults and minors with disabilities has been included in the Minimum Guaranteed Income (MGI) Legislation. They also provide the allowance of home care for people with disabilities, only if someone is receiving the MGI as a person with disabilities. In order to receive the MGI as a person with disability, one must be assessed by the SID department for the classification of their disability by type and extent[10].

However, there are several limitations in the field of social welfare, as well. A usual problem is the lack of staff, which results in long delays in the provision of services, and the difficulty of communicating with the staff. The Family Counselling and Support Services of the Social Welfare Services provide counselling only to high-risk families, involving family violence, substance use by parents, etc., with people not fulfilling these criteria remaining without support. Another problem is that community kindergartens may not accept a child with disability without assistant, with the parent being responsible to employ an assistant (Committee for the Protection of Persons with Intellectual Disabilities, 2023).

Regarding the basic allowance for adults and minors with disabilities (MGI), it is provided to people with moderate or severe disabilities. This is highly problematic for the families of

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[8] http://www.dmsw.gov.cy/dmsw/sws.nsf/home_el/home_el?opendocument
[9] http://www.dmsw.gov.cy/dmsw/dsid/dsid.nsf/index_en/index_en?OpenDocument
[10] https://www.wbas.dmsw.gov.cy/dmsw/ydep.nsf/home/home?openform

children with mild disability, as this benefit is used to finance private afternoon therapies (interventions by relevant state departments are not provided in the afternoon). Another limitation is that the application for the basic allowance for people with disabilities takes a long time to get assessed. Further, a significant problem is that the basic allowance is provided to people living in Cyprus for five years or more, excluding a big group of people with disabilities (Committee for the Protection of Persons with Intellectual Disabilities, 2023; Pancyprian Alliance for Disability, 2017).

Lastly, another limitation has to do with the philosophy of social welfare. Benefits are important but not enough. Benefit policy proves to be precarious as it might change depending on the economic conditions. Additionally, benefits overload the parents of the child with disabilities, placing on them with many responsibilities and with no adequate family support. Allowance policies must align with the education and support of the child with disabilities in order to eventually get integrated into the community without needing this allowance (Committee for the Protection of Persons with Intellectual Disabilities, 2023; United Nations, 2017).

Overall, closing this overview of services in Cyprus, considering the provisions as well as the problems observed, there are several services provided in Cyprus, which operate in a fragmentary way without substantial interconnection with each other. For example, there are no common records nor do the services communicate in any way when a family has to deal with more than one of them. A major common problem to all services is understaffing, resulting in huge waiting lists and insufficiency to help the public. These problems affect significantly people with disabilities and their families, who have to turn to many services at the same time to get their rights but they must also, on their own initiative, look for most of the services. Finally, a big problem that parents face is the lack of organized and substantial social and psycho-emotional support. All the above-mentioned services shape the picture of the current socio-cultural context in which parents live and experience the raising of their children with developmental disabilities.

1.7. The micro-socio-cultural context

1.7.1. Committee for the Protection of Persons with Intellectual Disabilities

As obvious from the above-mentioned services and policies, people with intellectual and developmental disabilities in Cyprus often encounter and have recurrently faced challenges in asserting their rights. In response to this situation and following the pressure from parents of persons with intellectual disabilities, Cyprus enacted special legislation in 1989 known as the 'Law 117/89 for the Intellectually Retarded'. This legislation designates the 'Committee for the Protection of the Intellectually Retarded Persons' as the authoritative body responsible for advocating and promoting the rights of individuals with intellectual disabilities in Cyprus. The Committee's name was changed by the Law 11(I)/2018 and was then renamed to Committee for the Protection of Persons with Intellectual Disabilities (Official Gazette of the Republic of Cyprus, 2018).

The main duties of the Committee for the Protection of Persons with Intellectual Disabilities are the continuous monitoring of the issues and problems faced by people with an intellectual disability and their families and the monitoring of all actions and decisions made by any state department, officials, organizations and persons regarding the issues faced by people with intellectual disabilities. Additionally, one of the main duties of the Committee is the registration of all persons with intellectual disabilities and the maintaining of record regarding the type of disability or any other information considered necessary concerning each individual with intellectual disability, their families and their activities. The Committee is also responsible for the design of programmes, in collaboration with the relevant state services, in order to promote the rights of people with intellectual disabilities. The registration of all institutions, organizations and services dealing with people with intellectual disabilities, the inspection and evaluation, in collaboration with the relevant state departments, of any institution or organization in which people with intellectual disabilities reside, are served or employed, are among the main responsibilities of the Committee, compiling for each of these activities the necessary reports. The Committee is also responsible for the monitoring of the employment, education, accommodation and overall welfare of people with intellectual disabilities. Counselling and guidance towards people with intellectual disabilities regarding the issues and problems they face, along with the provision and availability of services for them are among the basic responsibilities of the Committee. Regarding the families of people with intellectual disabilities, the Committee provides support to the families, offering counselling and guidance regarding the provision and availability of services for people with intellectual disabilities. The Committee is also responsible for maintain records and statistical data concerning people with intellectual disabilities as well as maintain a list of trustees to handle property belonging to people with intellectual disabilities (Committee for the Protection of Persons with Intellectual Disabilities, 2023).

To implement these objectives, the Committee for the Protection of Persons with Intellectual Disabilities consists of ten members appointed by the Deputy Ministry of Social Welfare, for a period of 4 years. Five members of the Committee are selected from the Pancyprian Association of Parents of Persons with Intellectual Disabilities, known as private members, and five members from the Civil Service, known as the state members. The state members are representatives of relevant Departments, namely the Deputy Ministry of Social Welfare, the Ministry of Education and Culture, the Ministry of Health and the Ministry of Finance. The President of the Committee is always a state member. The Committee for the Protection of Persons with Intellectual Disabilities employs both permanent and temporary contract staff to achieve these goals areas (Committee for the Protection of Persons with Intellectual Disabilities, 2023).

1.7.2. Early Childhood Intervention Coordinative Service (ECICS)

Early Childhood Intervention Coordinative Service (ECICS) focuses on children with developmental disabilities from birth to the age of 8 years old. This is a specialized liaison and support service for families of preschool children with developmental disabilities. The Service staff consists of a coordinator and 3 counsellors, who cover the needs of all districts of Cyprus. The Service operates with the support of the local municipalities and falls under the jurisdiction of the Committee for the Protection of Persons with Intellectual Disabilities (Committee for the Protection of Persons with Intellectual Disabilities, 2023).

The general goal of the Early Childhood Intervention Coordinative Service (ECICS) is the coordination of all involved professionals and services and the psycho-emotional support of the family of a child with a developmental disability, with the ultimate goal of creating favorable conditions for the development of the child. Early Childhood Intervention Coordinative Service (ECICS) is addressed to children of infant and preschool age 0-8 years (extension of services up to 12 years is provided), who present some minor or major developmental issues (Committee for the Protection of Persons with Intellectual Disabilities, 2023).

More common cases referred to the Early Childhood Intervention Coordinative Service (ECICS) are children with intellectual disability, chromosomal or genetic syndromes (such as Down, Prader-Willi, Angelman, Fragile X, Rett, etc.), problems due to prematurity, speech delay or communication problems, autism spectrum disorder, cerebral palsy, any form of developmental delay (global, psychomotor), attention deficit hyperactivity disorder or children presenting a high risk to develop the above problems or a combination of them.

The counsellor of the Early Childhood Intervention Coordinative Service (ECICS) is the connecting link between the family and the service providers with two main areas of responsibility: 1. the coordination of all services provided, ensuring the detection, the therapies and the rights of the child with developmental disabilities and 2. the psycho-emotional support of parents of children with developmental disabilities throughout the intervention. Specifically, the counsellor takes care of the investigation of the needs of the family and the child, the detailed information of the parents about the services provided in the public, private and voluntary sector and the organizing and monitoring of the interventions towards the child and the family. Additionally, the counsellor offers psycho-emotional support and counselling towards the parents and other family members, individually, in groups or at couples, empowering parents to take a central role regarding the appropriate decisions and actions for the benefit of the child with developmental disabilities. Among the counsellor’s responsibilities is the coordination of the services involved for the benefit of the child, the cooperation with specialists who assess, care, educate or offer therapies to the child and the promoting of the child’s and the family’s rights (Committee for the Protection of Persons with Intellectual Disabilities, 2023).

Overall, the Early Childhood Intervention Coordinative Service (ECICS) acts as the connection between parents, services and professionals. The Service provides important guidance to parents in one place, without having to reach out to several different services. The Service is quite accessible, with no time-consuming referral processes and without waiting list.

The main limitation of the Service is that the relevant state departments, the involved specialists, such as pediatricians, schools and preschool education (private or public) and any professional who comes into contact with children with developmental disabilities are not obliged to refer the family to the ECICS Service but they do so at their discretion, that is if they consider it is necessary. In other words, there is a structural institutional gap in the care of children with developmental disabilities, placing the responsibility on parents to seek appropriate support in case their child is diagnosed with a developmental disability.

The participants of this study were selected from the Early Childhood Intervention Coordinative Service (ECICS) and participated in the research project after giving their consent. The participants' selection process is further discussed in chapter 4.2.1.

1.8. Overview of the thesis' chapters

The aim of the study is to bring the experience of parents raising their children with intellectual disabilities to the fore. To achieve this, I started this research project by describing the context of disability in Cyprus, historically and socio-culturally, giving the picture of the policies and services provided in Cyprus for children with disabilities.

In chapter 2, I go through the literature review on the diagnosis of developmental disability, as approached by the medical and the social model of disability. I, then, examine how the literature describes the initial and long-term reaction of the parents to the diagnosis of their child with developmental disabilities. The literature review closes by studying the experience of parents, describing the feelings of parenting a child with developmental disabilities, the coping strategies of parents and the issue of stigma faced by parents of children with developmental disabilities. Lastly, I present how the literature describes the self-related issues of parents of children with developmental disabilities.

In chapter 3, I present the epistemological considerations of this research, that is phenomenology, social constructivism and how I approach the parents' experience through these 2 epistemological approaches. I continue by explaining the Social Representations Theory and the Symbolic Resources Theory, which helped me to theoretically understand the experience of parents.

In chapter 4, I introduce the methodology underpinning this study. I start with the rationale behind the use of qualitative methodology and continue with the research process, which includes the data corpus construction, the data collection methods, the pre-analytic procedure and the data analysis methods. I then discuss issues of transparency and quality of the study as well as ethical implications.

Chapters 5, 6 and 7 are the chapters of analysis, where I present the findings of this research project. Particularly, in chapter 5, I analyse the milestones of the parents' experience, that is the experience of the announcement of the diagnosis, the parents' interpretation of the diagnosis and the social dimensions of the diagnosis for the parents. In chapter 6, I present the findings of the exploration of the parents' experience, regarding their meaning on their experience, the feelings and the resources of parenting children with disabilities. In chapter 7, I discuss parents' self-related issues, such as their parental role, their loss of self while parenting their children with developmental disabilities and their coping with the challenges of parenting children with developmental disabilities.

In chapter 8, I present the conclusions of this study, by discussing the main ideas of ruptures, meaning-making and coping of parents of children with developmental disabilities, the practical implications and the limitations and future directions of this study.

Chapter 2: Literature review on parents' experience raising a child with developmental disability

This literature review outlines the experience of parents who raise a child with developmental disability. Parents of children with developmental disabilities face many challenges and stressors, further and more complicated than the usual challenges of parenting.

In this review I initially focus on understanding the child's diagnosis, through the concepts and models around disability, namely the medical and the social model of disability. I then present the literature on parents' reception of the diagnosis, initial and long-term. In the second sub-chapter, I examine the studies on parents' experience of raising a child with developmental disability. Firstly, I approach the parents' personal experience, thus their feelings concerning parenting a child with developmental disability. Secondly, I describe the ways parents find to cope through this situation. Then, I try to locate parents' experience within the social context, approaching the issue of stigma and stigmatising perceptions about parents of children with developmental disabilities. Finally, I outline the different roles that parents of children with developmental disabilities adopt and how do parents change through the experience of parenting a child with developmental disability.

2.1. The diagnosis of developmental disability

Approaching the child's diagnosis is a challenge, as it refers to a multidimensional and complicated concept (Albrecht et al, 2001). The way parents experience their child's diagnosis is decisively influenced by the prevailing philosophy and ideas around disability. Approaching disability is a dynamic phenomenon, represented by various models. The predominant are the medical and the social model of disability, which are presented in the next paragraphs.

2.1.1. Approaching the diagnosis. The medical VS the social model of disability

The *medical model* – also referred as the individualistic model of disability (Abberley, 1987) – approaches disability as an individual problem (Albrecht, 2006), as a tragic problem of an unfortunate individual (Oliver & Barnes, 2000). According to the medical model, people with disabilities are identified by their disability or their physical condition, depending entirely on specialists and needing help. Disability is, hence, considered an innate characteristic and the person is responsible for his/her defective physiology (Finkelstein, 1980). The medical model is based on the medical discourse or, more precisely, the 'restitution narrative', the idea that all conditions are treatable through medical intervention and the person with disability is totally identified through the concept of normalcy: a patient or a sufferer with a health condition that has to be treated. Disability can, therefore, be only viewed as a person's impairment (Adams et al, 2015). This model focuses on what a person cannot do, considering them as a problematic part of society and justifiably excluded (World Health Organization, 2002).

The medical model of disability has facilitated the formation of social representations of people with disabilities as defective, inferior and burdens of society, which Albrecht et al (2001, p. 91) describes as "the presumption of disablement as a burden". In the context of the medical model, the self-value is based exclusively on biological or physical features and group of people who are not fulfilling those requirements are arbitrarily degraded. As a result, exclusion of people with disabilities, unfavourable treatment or charity are inevitable consequences (Watson, 2004). Persons with disabilities are objectified and relegated, considered as passive and pathetic. Concepts such ugliness, tragedy, weakness, unreliability and even asexuality are attached to disability (Murugami, 2009). The absolute focus on individual limitations of physical impairment also generates certain reverse stereotypes around the medical model, such as inspirational stories about life lessons or personal triumphs (Albrecht, 2006; Young, 2014).

In recent decades and in response to the medical model, as a result of the rights movements of the 70s (discussed in chapter 1.4.1.), the *social model of disability* begins to diffuse. The social model of disability, named by M. Oliver (1983), approaches disability in equality terms. According to the social model, disability is a social construct (Case, 2001), which is determined by the limitation of an individual's opportunities to the life of his/her community on an equal basis with others, due to physical and social barriers. The source of disability, therefore, is located in the society and the environment, that places barriers in participation and equal treatment of people with disabilities (Oliver & Oliver, 1996). In this sense, Albrecht (2006) describes disability as a lack of citizenship, since people with disabilities cannot enjoy full rights and fully participate in social and political aspects of life. Disability moves from being an internalized personal problem and people with disabilities in need of care to being a social problem, focusing on disabling social and environmental barriers (Barnes & Mercer, 2004). Entering the social sphere, barriers could be met not only on the physical environment but also on people's attitudes and organizations or services.

Therefore, disability as a social construct originates upon the way society is organized and structured (Talbot et al, 2010) or, as Shakespeare (1996) suggests, is the outcome of social processes.

The social model of disability distinguishes the terms impairment and disability. The impairment is any kind of human dysfunction, bodily, mental or intellectual. Disability is the restrictions caused by the way society is built, resulting in the failure of meeting the needs of people with impairments (Oliver & Oliver, 1996). The objective for the social model is the restructuring of society in order to achieve the inclusion of all people, with and without disabilities (Barnes, 1996). This could include changing policies and practices, removing or balancing barriers and developing social acceptance and awareness (Albrecht, 2006). Consequently, the paradigm shift from the medical to the social model of disability marks the transition from the exclusive emphasis on the medical, physiological, and biological factors to the consideration of the multidimensionality and the consequences of each diagnosis, moving the disability approach “from the body to society” (Albrecht et al, 2001, p. 125).

The social model of disability defines a new way of approaching children’s developmental disability, as well. Developmental disability from being conceived as an individual attribute shifts into being conceived as a situation in which the child is unable to interact efficiently with his/her environment because of barriers imposed by society. Instead of types and categories of people – as well as children – with disabilities, the social model suggests structures of interaction within the social context (Rapley, 2004). The focus is on the difficulties experienced by children with developmental disabilities and their families due to disabling physical, cultural and socioeconomic barriers within the social, educational, leisure, healthcare context and the broader community (Goodley & Runswick-Cole, 2013).

It is interesting to note that each model of disability emerged at a different era, within different socio-cultural contexts. In chapter 1.5. I presented in detail how these models were historically shaped, and what contributed to their spread and establishment in different time frames. Besides, each model of disability reflects existing services, legislation, organizations and culture towards people with disabilities, including children with disabilities. This means that each model also influences the attitudes and the support that parents do or do not receive within the social context regarding their child's disability. This context is decisive in how parents experience raising their children with developmental disability.

2.1.2. Parents' initial and long-term reception of the diagnosis

The diagnosis of a child's developmental disability may concern a single one-off occasion but may also become a long process (Graungaard & Skov, 2007), with the latter being usually the case for young children (Runswick-Cole & Goodley, 2015). Schaefer & Bodensteiner (1992) note that 30 – 50% of final developmental disabilities diagnoses are uncertain, in terms of not being able to state a specific final diagnosis for many children. The diagnostic process often includes the possible changing states of the diagnosis, the communication of the information, the understanding of this information, the cooperation between parents and professionals but also other difficulties that may arise, namely difficulty in obtaining the appropriate diagnosis (Fallowfield & Jenkins 2004; Graungaard & Skov, 2007; Kuhaneck et al, 2010). Undoubtedly, the diagnostic process influences highly parents' emotional reaction, leading frequently to their frustration and increased stress levels during this often-exhausting process (Graungaard & Skov, 2007).

The parents' *initial reception of the diagnosis* has been found to generate feelings of anger, frustration, guilt, grief (Kearney & Griffin, 2001), sadness, rejection of the child, fear and/or anxiety (Arbouniotis, Koutsokleni, & Marnelakis, 2007).

Anxiety has been pointed out in literature, as the information of disability for their child is extremely stressful for parents (Solnit & Stark 1961; Case 2001). Parental stress has more been related to traumatic stress, following the traumatic experience of receiving their child's diagnosis of a chronic disability or other life-threatening illness (Casey et al, 2012). Landsman (1998) has described this traumatic experience as "the trauma of dashed expectations" (p. 76) as the expectancy of a healthy newborn child is abruptly and permanently lost. Parental stress is highly related to the child's diagnosis and the severity of the diagnosis, as exemplified by parents of children with autism and children with additional caregiving demands (Beckman, 1991) who often report experiencing higher levels of stress compared to parents of children with other diagnoses (Hayes & Watson, 2013; Dunst & Trivette, 1986). Stress of parents of children with disabilities has been found associated with children's unequal access to educational and vocational opportunities, social security and benefits (Blacher & Hatton 2001).

The child's diagnosis may also cause a shock response to parents, which Carr et al (2016) report as emotional turmoil. According to Fleischmann (2004, p. 35), parents describe the day they received the diagnosis as a landmark event, as the day their lives "were changed forever". The initial shock, following the diagnosis, is a common finding in many studies (Hodapp, 2005; Lainhart, 1999; Siegel, 1997). The literature reports the shock reaction often to be accompanied by a more general sense of denial (Ali et al, 2023; Marsh, 1992), feeling essentially unprepared for the arrival of a child with disability (DesChamps et al, 2020; Sekar & Valsala Gopalakrishnan, 2016).

Literature has also emphasized on parents' feeling of anger, usually related to guilt and questioning why (Krstic et al, 2015; Krstic et al, 2017). Fleischmann (2004) found that parents of children with autism narratives reflected feelings of guilt and anger. According to Hodge (2006), parents account the reason of their child's diagnosis as their own fault, leading to feelings of failing their responsibility as a parent. Anger, uncertainty and frustration but also devastation and feeling overwhelmed are among the most common emotional reactions that parents report following the reception of the diagnosis (Rabba et al, 2019). Anger also seems to be related to the diagnostic process per se, as a period of great challenge for parents, generating parental frustration and anger for some families (Klein, 2011).

Parental distress following the diagnosis has also been related to strong feelings of sadness, sorrow and disappointment (Fleischmann, 2004; Hodapp, 2005; Beckman, 1991). Minnes et al (2015) have pointed out the increased risk for depression for parents of children diagnosed with autism or intellectual disability. Feelings of helplessness and powerlessness are common between parents, stemming from a sense of loss for their child following the diagnosis – namely feeling as if they lost their child. Helplessness is also found to be related to a sense of weakness regarding their parental skills in raising a child with disability (Minnes et al, 2015) and a strong feeling of uncertainty concerning the future (Graungaard & Skov, 2007). In case of a long and unclear diagnostic process, an extra factor of ambiguity is, also, added to the situation, provoking stronger feelings, namely increased distress and depression (Reed et al, 2019; Wong et al, 2017). Depression is a core characteristic of traumatic stress, as it may arise from exposure to a traumatic stressor (Australia, 2019), like the diagnosis of a child with developmental disability. The diagnosis of a child may also initiate reactions of disbelief, mistrust to professionals or to each other and denial among parents (Graungaard & Skov, 2007; Fleischmann, 2004). Parental disappointment is also found to stem from the diagnostic process, in case of late diagnosis or regarding the timing of the diagnosis (Lopez et al, 2018). Most of the above-mentioned reactions should not be considered psychopathology but the beginning of an adaptation process throughout the traumatic change parents experience (Kroustalakis, 2005).

However, part of literature highlights, apart from the often-mentioned emotions of anger, guilt or denial, positive reactions as well. Parents report feeling satisfied for having their child not diagnosed with a more severe condition (Tait et al, 2016; Rossi, 2012). Parents' positive reactions are also related to confirming their own suspicion about something not typical in their child's development (Mansell & Morris, 2004), while validating at the same time their concerns (Sher-Censor & Shahar-Lahav, 2022). The literature also focuses on parents' feelings of relief, as a result of not feeling guilty about their parenting style, which is not to blame for the diagnosis (Lopez et al, 2008; Fowler & O'Connor, 2021). Feeling relief is found to be highly associated with professionals' attitude as well, when they keep a warm and respectful behaviour and reflect positive reactions towards parents (Anderberg & South, 2021).

Parents' *long-term reception* of their children's diagnosis has been broadly discussed in literature, as well. The term *acceptance* is originally used to describe the parents' conciliation with the feelings of loss of the idealized child (Hugger, 2009). This idea is borrowed by the Kubler-Ross (1969) stages of grief, stages which reflect the process experienced by the parent of a child with disability. After experiencing denial, anger, bargaining and depression, parents achieve a level of acceptance about who their child is, along with his or her difficulties (Hugger, 2009). Larson (1998) introduces the "paradox" of opposing forces concerning parents' reaction to their children's diagnosis: parents experience an internal fight where they love the child on the one hand and they wish to remove disability on the other hand, they try for the child's best progress while they acknowledge the permanency of the diagnosis, they preserve their hopes for the child's future while receiving negative information about it. Boström et al (2010) suggest that the acceptance of the child with developmental disability entails the capacity to merge "opposing thoughts and emotions about the disability as proposed by Larson (1998), but without being preoccupied with or dominated by the conflict of thoughts" (p. 6).

Dunst & Trivette (1986) and Dunst et al (1988) discuss about *family acceptance* towards the child, identifying it as the balance between recognizing the child's difficulties, trying to compensate these difficulties and avoiding any impact to the family dynamics. They have highlighted four characteristics of the parents' acceptance process: the appropriate parental perceptions of the child's potential and limitations, a realistic opinion about the child, the proper – not based on magical solutions – parental research for services and the availability to love the child with disability without rejection or overprotection. Kandel & Merrick (2007) focus, as well, on acceptance as a family issue, where the family reaches the stage of acceptance when they have successfully gone through a series of crises, such as the crisis of change, the crisis of personal values and the crisis of reality. After experiencing these crises, the family is ready to care for the child and the family itself, to resolve any conflict and to, finally, accept the child despite the disability.

However, other studies *criticise the term acceptance*. Primarily, acceptance seems to be related to a negative conceptualization of disability, directly referring to the medical model of disability where disability is experienced as a problem (McLaughlin et al, 2008). Respectively, parental feelings have been approached from a pathological view, ignoring the broader socio-political context of disability (McKeever & Miller, 2004). Larson (1998) describes acceptance as a “blanket term” (p. 868), used by professionals, not reflecting the process experienced by parents. Acceptance, denial and overprotection are dominant in the professionals’ discourse, all part of a standard healing process through the above-mentioned stages. Besides, parents discuss about a much more complicated experience, within a demanding parental role and with an uncertain future concerning the child’s disability (Larson, 1998).

At the same time, part of the literature proposes a *more hopeful discourse* around the issue of acceptance, talking about children’s development, the parents’ opportunity for personal growth and the “imperativeness of hopefulness” (Larson, 1998, p. 874). The representation of parents’ experience as the ultimate tragedy (Cousins, 2009) is broadly questioned (Murray, 2003; Mclaughlin et al, 2008; Avery, 1999). Instead, parents’ acceptance is reflected as a transition, moving from a negative consideration of the child’s diagnosis to a more positive one. Literature illustrates the initial negative parental reactions to be succeeded by positive and optimistic feelings, such as joy, satisfaction from the parental role and acceptance towards the child’s disability (Heiman, 2002). The whole parental experience of raising a child with disability is approached in terms of a complicate process of negotiation and understanding, but not simply or only as a painful process (Read, 1991, 2000; Traustadóttir, 1991). According to Moore (2012), parents shift from experiencing an adverse life situation to experiencing a chance for personal development. Parents are presented to maintain their hope (Sullivan, 1995) and disability is represented as part of the child, where acceptance concerns a process of entirely accepting the child with its limitations (Boström et al, 2010).

Additionally, parents’ level or process of acceptance vary significantly between parents but also may vary continuously over time concerning the same parent, not necessarily reflecting the grief stages (Heiman, 2002). Overall, some researchers discuss parents’ difficult emotions, such as sorrow, stress or guilt, but do not represent parents anymore as sufferers who carry the burden of their child’s disability. Rather, parents are represented as trying to make sense of their child’s disability, to share their experience and to advocate for their different children (Goddard et al, 2000; Case, 2001).

Part of the literature seems to adopt other terms to describe parents’ long-term reaction to their children’s diagnosis, such as *negotiation or resolution*. Case (2001) and Read (1991) suggest that parents negotiate, process and make sense of their children’s disability, not necessarily experiencing arduous stages of acceptance, denial or rejection. Vanobbergen et al. (2006) propose the negotiation model, where parents adopt the role of the negotiators for their children, developing more interaction with their children but also more reflection on their parenting role. Mclaughlin et al (2008) support that all concepts – including parenting, disability and ways of support – are under parents' negotiation. Resolution represents a process of acceptance, reaching a point where parents have experienced the stages of grief and are finally focused on the present and the future (Sher-Censor & Shahar-Lahav, 2022; Poslawsky et al, 2014; Milshtein et al, 2010). Therefore, parents' long-term reception of the diagnosis might be resolved or unresolved (Marvin & Pianta, 1996), with parents who do not reach resolution experiencing higher levels of depression and stress, poor coping mechanisms, false beliefs regarding the child's diagnosis (Sher-Censor & al, 2022; Reed et al, 2019; Krstic et al, 2015; Sher-Censor & al, 2017). Parents' resolution concerning the diagnosis is found to be related with several characteristics, such as acknowledgement of the emotional changes they experience, abandonment of the existential exploration about the diagnosis and determination to move forward in life. However, a resolved long-term reception of the diagnosis, does not necessarily denote that parents do not experience overwhelming or adverse feelings (Barak-Levy & Paryente, 2023). Besides, parents with resolved perception about the diagnosis are found to create a balanced representation of the child's abilities while they are more aware of the positives and negatives of their parenting course and their experience with their children (Pianta & Marvin, 1993). According to Lopez et al (2008) parental resolution regarding the child's diagnosis is considered to profoundly influence the parent-child interaction.

Overall, literature has distinctly approached the parents' initial as well as the long-term reception of their child's diagnosis with developmental disability. The parents' initial reaction to the child's diagnosis is mostly represented as a stressful and traumatic experience for the parents. Parents seem to react with shock while often expressing feelings of anger, uncertainty and frustration. Several studies focus on the parents' initial reaction to the child's diagnosis with sadness, sorrow and feeling helpless. Regarding parents' long-term reception of the diagnosis, parents' or family acceptance has been suggested as the achievement of balance, after experiencing the initial denial or anger feelings following the diagnosis. However, acceptance has been criticized as a non-representative and simplistic approach to the parents' long-term reception of the diagnosis. Instead, a strand of the literature suggests parents' negotiation or resolution with their child's diagnosis, as a process where they reach a level of acceptance and focus on the present and the future, acknowledging their children's limitations due to their disability.

The above-mentioned literature approaches acceptance as a linear process, where one stage follows the other. Whether it follows the stages of grief (Kübler-Ross, 1969) or sorrow and guilt (Larson, 1998), parents' acceptance has been described as reaching this point, by achieving or not acceptance. Further, existing research discusses acceptance in terms of accepting the diagnosis (Graungaard, 2007), giving less attention to the overall process of acceptance. The criticism towards the concept of acceptance resulted in the introduction of the terms negotiation and resolution. However, the proposed alternatives do not suggest anything essentially new, as negotiation or resolution suggest the achievement of a point where the parent is functional with the diagnosis of his child, but do not examine how this point is achieved. Besides, current research says little about acceptance as a complex ongoing process within the social reality. This kind of partial consideration reflects the lack of knowledge on parents' experience in total and their meaning-making process concerning their children disability. Thus this research project provides a valuable insight into parents' processes of meaning-making following the reception of the diagnosis. Studying parents' meaning-making may open up an understanding of the factors related to acceptance or any possible aspects of acceptance. Acceptance is about holistically integrating parents' experience of their child's disability within the given sociocultural context, meaning how the local socio-cultural environment influences and is influenced by parents' ongoing process of relating with the child's diagnosis.

2.2. The parents' experience of raising a child with developmental disability

This chapter aims to present the literature around the parents' experience of raising a child with developmental disability. Parenting a child with developmental disabilities is a multifaceted experience, approached from various perspectives. Firstly, I discuss the feelings experienced by parents of children with developmental disabilities. Then, I examine the ways parents cope throughout this parenting experience. The next chapter aims to analyse the concept of stigma and the stigmatising perceptions about parents of children with developmental disabilities. Finally, I attempt to approach the issue of parents' change and the transformation that parents experience when raising their children with developmental disabilities.

2.2.1. Feelings of parents of children with developmental disabilities

The existing literature suggests that parents of children with developmental disabilities may experience *various and intense feelings*, with anxiety and depression being the most prevalent feelings experienced by parents (McLaughlin et al, 2008). However, the experience of parenting a child with disability is full of diverse yet sometimes inevitably overlapping with each other and interrelated feelings, which I try to illuminate in this chapter.

The literature consistently suggests that parents of children with developmental disabilities – including autism and ADHD (Mount & Dillon, 2014; Kuhaneck et al, 2010; Hutchison et al, 2016) – experience *increased parental stress* (Lopez et al, 2008; Crnic et al, 1983). Parental stress is, typically, a key ingredient of any child-rearing experience, with or without disabilities, which might entail several challenges. However, parenting a child without disability may signify a gradual decrease of stress as experience is built up and parental self-efficacy grow (Deater-Dechard, 2004). This may explain why parents of children with disabilities experience more stress on their parenting role (Hutchison et al, 2016). In some cases, parents describe a state of perpetual crisis, due to the stress fluctuation and the non-remitting daily challenges (Mount & Dillon, 2014). However, other studies report stability over time, as the child grows older, regarding parental stress and family functioning (Dyson, 1993). The primary source of parental stress seems to be found to the kind of behavioural problems related with the child's diagnosis and the lack of efficiency parents feel when trying to respond to those behaviours (Sharpley et al, 1997). Parents' effort to accommodate daily challenges and to find ways for their child to function within the given environmental circumstances causes ongoing emotional distress, tension and anxiety within the family (Lainhart, 1999). Olsson & Hwang (2003) describe the birth of children with disabilities as a permanent stressful event in parents' life, highly influenced though by the type of disability – whether for instance is autism or Down syndrome. Other factors that seem to underpin parental stress level when raising a child with disability include social isolation, financial difficulties and the ineffectiveness or inaccessibility of services (Montes & Halterman, 2007; Woodgate et al, 2008). Marital dissatisfaction (Hogan et al, 2012) and divorce (Mauldon, 2012) have also been associated to parenting a child with developmental or other disability, resulting as well in parents' increased stress.

How stress impacts on the parents and the family are highly associated with their understanding of the situation, the family's coping resources and parents' beliefs (Crnic et al, 1983). The stress of parenting a child with developmental disability has also been explained by Hill's (1958) double ABCX model. The model describes a relational representation of the family crisis (X) – namely the way family responds to the crisis of disability – as an interactive outcome of three factors: the initial stressor event (A), the family's resources regarding dealing with crises (B) and the family's perception about the stressor (C) (Behr et al, 1992; Patterson, 1993). All factors are considered prior and following the crisis, to integrate the perspective over time, explaining the term 'double' on the model's name (Lavee et al, 1985). The model's pre- and post-crisis view allows to approach stress as a process (Hansen & Johnson, 1979), not like a single occasion, and deeply understand it. Apart from describing parental stress, the model has also been used as a tool of identifying how families adapt and cope with stressful events (Lavee et al, 1985; Albrecht et al, 2001), which is further discussed in chapter 2.2.2.

Another group of feelings highlighted in literature that parents of children with developmental disabilities experience is *sadness, chronic sorrow and disappointment* (Fleischmann, 2004; Hodapp, 2005; Beckman, 1991). According to Olshansky (1961), chronic sorrow is between the main emotional parental reactions, as an expected response to an unanticipated situation. Parents' chronic sorrow seems to be related to several factors, like vulnerability, hopelessness, isolation but also negative messages from others as well (Kearney & Griffin, 2001). McLaughlin et al (2008) suggest that parents experience several difficulties and struggles, which makes them feel vulnerable or at risk. Boström et al (2010) emphasize the worry, the pain and the sense of burden that this negative affective experience includes. In addition to feelings of pain, parents commonly report loneliness (Ergün & Ertem, 2012), as a result of the isolation, the social marginalisation, the stigmatisation and the disempowerment they experience (Solomon et al, 2001). The increased demands of caring for a disabled child – namely financial difficulties, strained family relationships, modified work and leisure activities, limited social life and greater time constraints (Olsson and Hwang, 2003) – inevitably lead to relevant emotions of distress. These negative aspects of parenting a child with disability have been mainly described in literature as the caregiver burden (Hastings & Taunt, 2002; Green, 2007).

Other researches have pointed out parents' depression (Burden, 1980; Carpiniello, 1995), as a typical response of parents raising children with developmental disabilities (Krstic et al, 2021; Roach et al, 1999; Mount & Dillon, 2014; Crnic et al, 1983). Clinically-wise, parenting a child with disabilities is more strongly associated with depressive symptomology than caring for a typically developing child (Raina et al, 2005; Gallagher et al, 2008; Cantwell et al, 2015). Cummings & Davies (1994) suggest that mothers of children with developmental disabilities present increased depressive symptoms and a limited feeling of maternal satisfaction, compared to other mothers. Pain and suffering seem to be an ongoing condition – “suffering through life with their disabled children” (McLaughlin et al, 2008, p. 14) – experiencing a profound helplessness.

Raising a child with disability has also been *described with grief terms* as parents are found to experience the loss of the expected ‘perfect child’ (Solnit & Stark, 1961). According to Benedek (1959), the child is the hero that each parent envisions to raise, an expectation that is defeated when a child is diagnosed with a developmental disability. Parental reactions to their child’s disability have, therefore, been parallelized with the stages of loss, including anger, guilt and fear (Partington, 2002), holding parents in an extended or ongoing grief reaction (O’ Brien, 2007). A different, more solution-focused view of the grief process, namely the pervasive time-bound models of grief and mourning, has also been used to present parental responses to having a child with developmental disability. According to this model, the failure to accept the loss is maladaptive and in need for intervention; the final acceptance of the loss, on the other hand, is the essential component of the process towards the parents’ healthy adjustment (Kubler-Ross, 1969; Irvin et al, 1976).

Shame, guilt and denial, have also been found as key elements of parents’ experience raising a child with disability (Krstic et al, 2015; Mount & Dillon, 2014; Kearney & Griffin, 2001). Using a psychodynamic perspective, literature has related guilt to parents’ behaviour towards the child care, whether too passive, interpreted as underlying guilt or denial, or too involved, interpreted as a guilt reaction due to feelings of responsibility about their child’s disability (MacKeith, 1973; Solnit & Stark, 1961). According to Lazarus & Lazarus (1994), guilt is the result of parents’ failure to meet their “ideal” self and their narcissistic expectation of the “ideal” child, projecting their own selves to their child. Having a child with disability signifies a new reality for parents, who are called to build a new identity, a new self. Feelings of shame, guilt or invalidation may arise throughout this process.

Lately, a wide part of literature challenges the above-mentioned focus on stress, sorrow and tragic stories of parents of children with developmental disabilities. Research has recently identified *positive-based feelings* of parenting a child with disability (Kearney & Griffin, 2001; Ferguson, 2002). Additionally, literature has been broadening to parents’ narratives, rather than just professionals’ (Ferguson, 2002; Goddard et al, 2000), and to more critical perspectives, rather than strictly clinical. As Goddart et al claim (2000, p. 275), this is an effort to “depathologize the experience of being the parent of a child with disability”. This might also be related to the difficulty to represent the experience of parenting a child with disability without effectively confirming the views of others that having a child with disability is a terrible thing, as suggested by Ryan & Runswick-Cole

(2008). According to them, the prevailing narratives about parenting a child with disability obstruct the exploration of perspectives beyond negativity, with limited consideration of the other, more positive, dimensions of mothering a child with disability.

According to Kearney & Griffin (2001) parents describe their experience of raising a child with a developmental disability as *positive*, *maintaining their hope* and considering their children a source of joy. Turnbull et al (1988; 1993) emphasize how children and other members of families with disabilities are a positive contribution, a source of strength, joy and fulfillment for the family. Additionally, parenting a child with disability has several positive outcomes (Beresford, 1994) as improving adaptive characteristics (McLaughlin et al, 2008), appreciation of important things in life (Giulio et al, 2014), increased tolerance and understanding (Stainton & Besser, 1998), more conscious behaviour towards the other children (Olsson and Hwang, 2003) and parental or general empowerment (Fleischmann, 2001). Interestingly enough, positive feelings seem to increase parents' ability to take action (Knox et al, 2000), but also vice versa, namely parents' action enhances their perception of their efficacy and finally gives them a more optimistic perspective of their situation (Fleischmann, 2004). Lalvani (2008) also underlines the positive aspects of raising a child with developmental disability, such as positive perceptions, increased family closeness, personal development and general growth in their lives.

Another interesting approach of parents' experience of their children with developmental disabilities is *the concept of "tensions"* (Kearney & Griffin, 2001), where parents do admit feelings of sorrow and anguish but also emphasize on feelings of hope, love, strength and joy. Dipoles of opposite emotions are therefore created – hope and no hope, defiance and despair – which are described by authors as "a tension between the experience of joy and sorrow" (p. 587). These contradictory emotions have been described by Larson (1998) as the "embrace of a paradox": mothers of children with disabilities do find ways to deal with the opposing feelings about their children's permanent condition and, at the same time, they find solutions and remain optimistic. This conflict between negative and positive feelings is obvious in parents' narratives, proving that raising a child with disability is not a static or a standard but a dynamic and complicated experience full of intense feelings.

Another perspective about parenting a child with disability, apart from the typical stressful and traumatic event of the family, is the concept of *post-traumatic growth* or the growth through adversity (Joseph et al, 2006). Similarly, Linley (2004) suggests that personal growth is an element found in suffering. Even the stages of loss, that parents experience, can be considered as a process of reconstruction, development and, finally, fruitful transformation (Kubler-Ross, 1969).

Joseph et al (2012) introduces the organismic valuing theory, where he describes in detail post-traumatic growth: a highly demanding and traumatic event, such as their child's disability, may be the trigger for parental personal growth or, possibly, the positive change (Joseph et al, 2006). Following a traumatic event, people improve their relationships, review their opinion about themselves and experience changes in their life philosophy. Using these resources, when people experience an adverse situation, they accept the change while trying to rebuild and redefine themselves, in order to achieve personal development and psychological well-being (Joseph & Linley, 2005; 2006). In that sense, post-traumatic growth arises as a result of post-traumatic stress and "involves the rebuilding of the shattered assumptive world" (Joseph, 2012; p. 818), thus the acceptance of the adversity and the reconstruction of a new and more resilient self. Post-traumatic growth allows people to develop resilience in turning points in their lives, without necessarily or automatically discard the memories, the distress or the grief experienced.

Overall, the above-mentioned literature on parents' reception of the diagnosis as well as on their feelings on raising their children with disabilities, appears to deconstruct the previous narrative of chronic sorrow and distress that parents experience (Kausar et al, 2003; King et al, 2006) and rather depathologize the experience of parenting a child with disabilities (Kearney & Griffin 2001; Bennett et al, 1996). Research does not deny stress and sadness, but extends the scope of the literature to include more positive focuses on rearing a child with disabilities (Matson et al, 2020; Hastings & Taunt, 2002). This shift has also been observed in the literature related to parents, where parents' identities are represented as more involved and less tragic, in denial or burdened (McLaughlin et al, 2008). Positive and negative perceptions may co-occur, comprising different dimensions of the same experience, where parents of children with disabilities do feel greater stress than parents of children without disabilities and – at the same time – positive emotions (Hastings & Taunt, 2002). This clear turn to depathologizing the parental experience also coincides with or follows the transition from the medical to the social model of disability, which depathologized disability (chapter 2.1.1.). Additionally, the parental care of children with disability isn't approached anymore as a burden, as long as disability is no longer considered a problem, a source of burden and a tragedy (McLaughlin et al, 2008).

Consequently, it is obvious that previous research almost fails to consider that raising a child with disabilities evokes feelings of joy and satisfaction along with sadness and struggle (Goddart et al, 2000). Additionally, recent research, while discussing positive emotions, leaves a gap as to the association between them, thus in what ways parents experience conflicting emotions. Furthermore, research does not take into account how the experience of parents is affected by their interpretation, thus parents' meaning-making of raising a child with developmental disorders.

This research project focuses on all aspects of the parents' experience, thus examining parents' experience as an overall process of meaning-making by not emphasizing only the negative aspects. Considering the parents' experience as a whole means that I am interested in examining how the distinct elements of the parenting experience – namely parent's reception and interpretation of the diagnosis, as well as parents' feelings and meaning of their parenting experience – how these aspects of their experience interact and relate to each other. As Antonovsky claims, there is "a need for new questions and paradigms focusing not only on risk and breakdown but also on psychological health and what promotes it" (Antonovsky in Helff & Glidden, 1998, p. 461). There is a need for research not emphasizing on the individual problem but focusing on understanding the whole process. This is the perspective I approach parents' experience from, which I analyse in the next chapters.

2.2.2. Coping of parents of children with developmental disabilities

Despite the adversity, the significant stress and other consequent intense feelings of raising a child with developmental disability, parents usually find ways to cope and, most of the times, cope successfully (Marcus et al, 1997; Bayat, 2007). Besides, the adoption of coping strategies may impact and finally decrease parental stress (Lopez et al, 2008), offering them a more positive view of life (Tarakeshwar & Pargament, 2001). However, it is interesting to note that coping doesn't always have the same efficacy nor is necessarily a conscious process (Graungaard & Skov, 2007). This subchapter attempts to describe the ways parents cope with their children's developmental disabilities.

Literature has pointed out three main types of coping adversity in general: problem, emotion and perception focused coping (Daniels, 1999; Lazarus, 1996). For parents of children with developmental disabilities, problem focused coping aims at decreasing stress by changing the nature of the problem or the situation. Examples of problem focused parents' strategies of coping include seeking advice or support, collecting information or learning new skills (Mount & Dillon, 2014; Graungaard & Skov, 2007). Emotion focused coping – which Anuar et al (2021) report as the most frequently used by parents – intends to reduce the parents' emotional distress caused by the situation. Expressing feelings, praying, withdrawal or avoidance can be some typical emotion-based ways of coping.

Perception focused training emphasizes on the parents' perception about the situation, aiming at changing his/her understanding of the situation. Coping strategies categorized as perception focused may be evaluating beliefs, identifying positive aspects, or reframing in a positive way (Graungaard & Skov, 2007). Barak-Levy et al (2015) approach each coping style – emotional, cognitive or problem/active style of coping – as a continuum, whether parents have reached a resolved or an unresolved reaction about their children's developmental disability. Problem focused coping strategies are generally found to be preferred by young parents, whereas older tend to use more emotion focused coping strategies (Gray, 2006). According to Mount & Dillon (2014), mothers of children with autism are presented using more problem focused coping than fathers. Additionally, there is a tendency by mothers to prefer more social ways of coping, namely social support, while fathers seem to choose more avoidance coping, such as restriction of social interaction (Glidden & Natcher, 2009). Whatever type of coping strategy parents use, literature confirms that they tend to change coping strategies over time (Gray, 2006).

Literature highlights *social and family support* as one of the main and most often used coping mechanisms by parents of children with developmental disabilities. Parents who receive broader family and social support have been found to feel less stressed and to present better adaptation skills, which impacts the whole family (Kuhaneck et al, 2010). Dunst and Trivette (1988) describe this support network, including family members, friends, neighbours, professionals and educational context as "help-givers", who can provide a family with material aid, emotional support and information (Schradle & Dougher, 1985). Other researchers discuss about support from informal sources, such as family members, neighbours, church members, and online communities (Billen et al, 2023). Support can also include social services, support groups, networking or other. Additionally, social support has been related to generally improving parents' mental health (Boyd, 2002) or preventing depression and stress (Gray & Holden, 1992). In a study examining the perspective of mothers of children with autism (Buchholz, 2023), social support is also found to be positively related to the development of psychological resilience.

Networking, specifically with other parents who have children with disabilities as well as family and friends, is also found to be another significant way of social support (Ali et al, 2023). Twoy et al (2007) emphasize the high frequency (93%) of seeking advice or communication with other parents. Having a strong support system is considered critical for parents as it allows them to feel less overwhelmed and vulnerable (Rabba et al, 2019; Fowler & O'Connor, 2021; McCutcheon, 2019), relieving them from stress and contributing essentially to their coping (McLaughlin et al, 2008). According to Tomiyama et al (2018), networking among parents of children with disabilities, participation in parents' support groups or other social support interventions produce positive results, such as decrease of parents' anxiety and depression levels. Parents' networking might nowadays be personal or online (Fleischmann, 2004). According to Billen et al (2023), parents search for online networks for exchanging their experiences with other parents who have been through the same one, especially when their children are diagnosed with a rare disorder and is more difficult to locate such social support locally.

Obtaining knowledge about their child's condition is another effective coping mechanism that parents are widely found to use. Information can be related to developing new skills, investigating alternative therapies, understanding the professional information, communicating with professionals, exploring services and administrative procedures and many more (Graungaard & Skov, 2007; Kuhaneck et al, 2010). According to Taanila et al (2002), knowledge/information-seeking, a problem focused coping strategy, has a general positive effect on how parents react regarding their children disability. On the contrary, lack of knowledge has been described as a stressor from mothers of children with autism, while knowledge has a stress relief function, allows them to educate others and finally advocate for their own children (Kuhaneck et al, 2010). Additionally, obtaining knowledge allows parents, especially mothers, to develop self-efficacy, raise their confidence and decrease stress feelings on their parenting role (Kuhn & Carter, 2006). Knowledge seeking and educating themselves. The knowledge and information that parents acquire is nowadays easily available and accessible online, via various digital platforms (Dreyfus & Dowse, 2020).

Sharing is also an important coping mechanism for parents of children with developmental disabilities. Specifically, sharing the knowledge obtained from information-seeking (Kuhaneck et al, 2010) have been reported as a significant tool by parents. Sharing their experience of parenting a child with disability helps parents relieve the emotional load attached to the process of parenting a child with disability (Pennebaker & Seagal, 1999). The empathy displayed by the listeners they share with their experience has a therapeutic function (Fleischmann, 2004). Some parents also choose to publish their experience, mainly through the internet. Publishing their experience is found to aim at helping other parents and eventually developing support networks. Additionally, sharing publicly their experience has been found to alleviate parental stress, as they no longer perceive themselves as victims but as active fighters (Fleischmann, 2004). Sharing through the internet, namely through digital platforms, social media or health-related applications, whether regarding information exchange or social support between parents is found to be closely associated to parents' feelings of empowerment (Gruebner et al, 2022). According to McLaughlin et al (2008), the use of the Internet from parents of children with disabilities allows them to gain a sense of belonging, through participation in parents' online communities – along with other uses, such as information seeking and support – and “maintain a reasonable quality of life” (p. 115) in the long-term. Nicholl et al (2017) suggest that parents’ systematic use of the Internet and the social media contributes to developing parent-to-parent support, which ultimately increases their understanding about their child’s diagnosis and improves their decision-making, care and management skills regarding their children’s issues.

Another important coping mechanism of parents of children with developmental disabilities is *creating personal time*. Literature emphasizes the substantial role of personal time, especially for mothers, including exercise, meeting friends, shopping, going out or spending time with their other child/children (Kuhaneck et al, 2010). Socializing as a couple and spending time together is also found to be important for parents (Higgins, Bailey & Pearce, 2005). Personal time may also concern working, any kind of personal recreation or other activities (Gray, 2006; Mount & Dillon, 2014). Parents seem to greatly benefit from having personal time, as the emotional load of parenting a child with developmental disability is released and their general mental health is improved (Kuhaneck et al, 2010). Additionally, keeping some distance from the child with developmental disability and finding ways to ‘escape’ – such as time spent in exercising or with friends – seems to be significantly effective and chosen by parents (Kuhaneck et al, 2010; Sivberg, 2002). In general, any activity apart from caregiving and parenting the child with disability functions as a useful self-care coping practice for parents and help preserve their mental and physical health (Merluzzi et al, 2011). According to Gorsky (2014), self-care has been found to decrease parents’ stress feelings and increase family resilience.

Literature also focuses on the significance of religious coping for parents of children with developmental disabilities (Twoy et al, 2007; Hastings et al, 2005). Religious coping may include faith in God or other belief system, spiritual development and/or involvement in religion-related activities or rituals (praying, attending church, pilgrimage or other). Vadasy & Fewell (1986) suggest that religious beliefs may serve as a stronger source of support than religious practices, namely attending church. Pargament et al (1990) propose that religion plays an important role in understanding or dealing with significant negative life events. In an effort to analyse what exactly is helpful, Pargament et al (1990) claim that religious faith can offer a source of meaning, a supportive partner and a “master motive” (Allport, 1950, p. 81). Religious practices and faith are also found to contribute to parent's sense of empowerment and confidence in their ability to provide their child with the necessities for a happy future (Bennett, 1995). Other researches focus on the function of religion and meditation as a stress relief technique for parents of children with developmental disabilities (Kurowska et al, 2021). Religion is frequently reported by parents of children with developmental disabilities (Kuhaneck et al, 2010) and can be applied as an emotional coping mechanism, offering comfort and relieving feelings of anger, guilt and shame, regarding the child’s diagnosis, but also as a perception focused coping mechanism, offering meaning. Bennett et al (1995) suggest that religious belief and practices may directly influence parent's ability to cope, by enhancing their hope and personal strength. According to McIntosh et al (1993), religion has an essential role as a recourse in coping with any adversity. Further, the support context created around religion, such as the members participating in religious practices, serves as a support and safe network and another coping resource for parents (Bennett, 1995). However, the denial of religion has been also reported as a coping mechanism, since some parents seem to doubt or deny their religious faith because of their child’s experience (Graungaard, 2007), experiencing it as a betrayal, rejection or disappointment following their child’s diagnosis.

Some studies discuss more specific characteristics of parents who use religion as a coping mechanism. Anuar et al (2021) describe slight differences concerning parents’ level of stress related to their religious doctrine, whether Muslim, Christian or Buddhism, with the last two experiencing higher levels of stress. Dura-Vila et al (2010) emphasize on the significance of spirituality in general, and not only religion, as a good coping resource for parents of children with disabilities. Additionally, parental age also appears to play an important role, as parents seems to intensify their religious practices and seek religion as a relief as they grow older (Cless et al, 2018; Nurmalita, 2019).

Adopting coping mechanisms has multiple gains for the parents. Primarily, coping has been found to have a significant emotionally comforting function, as it decreases stress in parents of children with disabilities (Jones & Passey, 2004; Graungaard & Skov, 2007). Parents of children with disabilities are found to experience great levels of stress or other emotional reactions; finding ways to cope with the situation improves significantly parents’ general well-being (Taanila et al, 2002). On the contrary, avoidance of dealing with the child’s difficulties arising due to disability may be related with increased parental anxiety, stress and depression (Mount & Dillon, 2014). On a practical level, the absence of any coping mechanism is found to influence negatively the child with disability, as parental stress creates a stressful environment for the child (Hadadian & Merbler, 1996). Non-effective care-giving towards the child but also delays in diagnosis have also been found to concern families with limited coping strategies (Taanila et al, 2002; Graungaard & Skov, 2007). According to Kandel & Merrick (2007) coping strategies change over time, depending on the developmental stages of children with disabilities, with families of young children with developmental disabilities achieving an adaptive and positive functioning. Families' coping influence greatly the development, including individual functioning and social inclusion, of children with developmental disabilities.

Overall, the literature discussed in this chapter focuses on the parents' coping mechanisms and the coping styles used – namely problem, emotion or cognitive-focused coping. However, existing literature does not emphasize on parents' meaning-making processes concerning their children developmental disability as well as their own experience parenting their child with disability. This study aims to explore the parents' coping strategies but also in what ways this coping helps or allows parents to construct meaning regarding their children's disability, and how this meaning help them cope. Parents' meaning-making will be considered not as a one-off process, but as a continuous course ruling any phase of the parents' experience, including the diagnostic process, their experience parenting a child with disabilities, the resources they use and their self-change throughout this experience. Consequently, this research intends to study the parents' ability to cope with the experience of their children's disability and how this ability is constructed via the meaning they attribute to their experience.

2.2.3. Stigma and stigmatising perceptions about parents of children with developmental disabilities

2.2.3.1. Understanding stigma

Stigma is defined as a discrediting attribute, which gives a person a special position, spoiling his/her normal identity (Corrigan et al, 2003). This attribute presents the person as deviating from the typical social norm, on a specific dimension which is negatively valued. The person's whole identity is defined by this dimension, making the person less valuable. This profoundly degrading mark differentiates the stigmatised person "from a whole and usual person to a tainted, discounted one" (Goffman, 1963; p.3), considered as an "unwanted difference" (Kayama et al, 2017; p.128). Stigma becomes the dominant attribute of the stigmatised person, regardless of any other attribute he/she may have. According to Goffman, stigma is a social construct, as society formulates categories, establishes the means of classifying individuals into these categories and assigns specific meanings to a certain range of attributes, defining some as normal and ordinary and some others as disparaging (Goffman, 1963). Stigma is also described as a social disease, affecting the stigmatised person with a negative status, giving him/her a different and negative social identity (Corrigan et al, 2003). Link & Phelan (2001; 2013) introduced the term 'stigma power', in order to describe the 'source of power' that stigma represents, which allows 'the stigmatizer to control the stigmatised person' (p. 534). It is, therefore, an issue of power imbalance, as a result of status loss, stereotyping, labelling and discrimination.

Literature suggests the consequences of stigma within the social context, as the separation of social groups is enhanced, stereotypes are developed, resulting in possible exclusion, discrimination, racism and human rights violation (Pescosolido et al, 2008; Van Brakel, 2006). Stigma has several consequences towards the stigmatised person as well, since it seems to have a tremendous effect on the stigmatised person's self-perception, internalizing negative stereotypes about them in the social field (Crocker, Major & Steele, 1998). This internalization of the stigmatising labels can generate inferiority feelings (Allport, 1954), rejection anxiety, depression or social phobias to the stigmatised person (Mendoza-Denton et al, 2002; Deaux, 2006; Blackburn & Twaddle, 1996; Van Brakel, 2006). Discussing the relationship between self-perception and others' evaluation, Cooley (Franks & Gecas 1992) introduces the looking-glass theory, according to which the development of one's self is accomplished through how others are evaluating him/her, therefore through their interpersonal interactions. A key mechanism for developing self-perception is how the individual feels he/she is being treated by important others (Mead, 1934). The fear of being negatively evaluated prevents stigmatised persons from challenging the discrimination they face in their lives (Dovidio & Gaertner, 1998). Acknowledging that they are stigmatised is a sufficient threat to the individual's sense of adequacy and competence. Consequently, the stigmatised person acquires a victim role, a defensive and intimidating role, risking abuse or even harassment. According to Link & Phelan (2013), when people experience stigmatization, the consequences of stigma can be as painful and debilitating as the stigmatising attribute itself.

2.2.3.2. Disability as a stigmatising attribute

According to Goffman (1963), disability is a stigmatising attribute. Stigma places and keeps people with disabilities in a role of continuous passiveness and submissiveness. People with disabilities are considered highly dependent from people without disabilities, possibly useless for the economy and their exclusion and oppression from the several social barriers becomes a natural consequence (Finkelstein, 1980; Abberley, 1987). These negative attitudes towards people with disabilities limit their efforts to develop skills and, finally, represent a real obstacle to fulfilling their preferred social roles (Siller, 1976).

Goffman (1963) distinguishes between the well observed stigmatised groups, such as people with different skin colour, and the non-observed, such as people with invisible disabilities. Jones et al (1984) describe this stigmatising quality as concealability, namely how obvious the stigmatising attribute is to others. A particular trait of people with developmental disabilities as a stigmatised group is that they do not strictly belong to one of those categories, with some of them being in the observed and some in the non-observed category. Runswick-Cole & Goodley (2015) point out the "childlike" attribute of people with learning disabilities, with substantial consequences on their lives, such as denial of the right to vote, to work and to make choices regarding their lives, placing them in a particular stigmatised position. According to Edgerton (1967), developmental disability denotes a shattering stigma for people presenting the disabilities and, therefore, stigmatised. The severity of disability is also found to be positively related with stigma (Ouellette-Kuntz et al, 2010). Ali et al (2008) suggest that people with developmental disabilities acknowledge the stigma of their disability and the relevant social consequences. However, many people with developmental disabilities try to hide or reject this identity, in an effort to cope with stigma (Gillman et al, 2000). Contact between people with and without disabilities is considered to have a great effect, improving the understanding towards people with disabilities, increasing positive attitudes and decreasing stigma (Blundell, 2016).

2.2.3.3. Understanding secondary stigma

According to Glidden (1993, p. 482), "a family with a child who has a disability is a family with disability". This quote describes efficiently the concept of secondary stigma. The secondary stigma – initially framed as courtesy stigma – impacts on the close environment of the stigmatised person, namely their family, friends, carers or others. Jones et al (1984) suggest that the stigma is transferred to the people around the stigmatised person. Goffman (1963) defines the secondary stigma as 'stigma by association', meaning that a person loses his/her respect and is degraded by society due to his/her association with a stigmatised person. Literature proposes that the family, and especially the parents, as the persons directly and mostly communicating with the stigmatised child, automatically receive a negative status (Read, 2000), accumulate all relevant social barriers of stigma and place themselves in a minority position (Marshak & Seligman, 1993).

Murray & Cornell (1981, p. 201) use the term 'parentalplegia' to accurately describe the effect on parents: "children having conditions of mental retardation or other handicaps involving physical deficiencies are likely to be causes of a secondary handicapping condition involving the parents". The particular role of parents, as shapers, educators, carers and many more, and the unique association with their child generates a special form of secondary stigma as they are stigmatised by their relationship with their child, a committed form of relationship with no degree of choice (Gray, 2002). Lecavalier et al (2006) describe secondary stigma as another severe problem among many others – namely the child's problematic behaviour, the financial burdens and more – that parents of children with developmental disabilities need to resolve. Families of children with disabilities may also be considered dysfunctional (Runswick-Cole, 2007), as families with a special attribute due to their child member with disability.

The stigmatising perceptions towards parents of children with disabilities play a significant role on how parents experience stigma. Literature confirms that parents of children with developmental disabilities usually experience stigmatising reactions from others (Birenbaum 1970, Scambler & Hopkins, 1986). Ryan & Runswick-Cole (2008) argue that mothers of children with disabilities find themselves in a marginal position, since often they themselves are without disabilities, still encountering forms of disablism, through parenting their children with disabilities. Green (2003) suggests that one of the first reactions of adults and children to the presence of people with disabilities is discomfort due to their obvious difference, which subsides noticeably as they interact with each other. Negative public attitudes towards their child or towards disability in general may result in parents feeling that their child is disrespected (Stewart et al, 2017). This seems to be highly associated with the child's behavioural problems, as child's aggressive behaviour has been found to enhance parents' experienced stigma (Gray, 2002). Child's challenging behaviour can cause distress to parents, making them feeling powerless and, finally, isolated. Specifically, children's behaviour is perceived as disobedience and, thus, rightfully stigmatised and differentiated (Aubé et al, 2021; Gray, 1993). Parents are seen as directly involved, perceived as failing in their parenting role, having contributed to this behaviour and are also stigmatised (Farrugia, 2009; Broady et al, 2017). Richardson & Fulton (2011) report negative thoughts, hostile and stigmatising attitudes towards children with disabilities and their families. Interestingly enough, different stigmatising experiences have been reported between mothers and fathers: even though both parents experience secondary stigma due to their children's disability, mothers describe encountering hostile staring, avoidance and rude behaviour whereas fathers did not state experiencing similar behaviours that often (Gray, 2002). The reason behind this difference seems to be related to the mothers' role as the primary caregiver, her role as the parent with the most public encounters with the child and the parent who is considered the most responsible for the child's problems whatsoever (Gray, 2002).

Concerning the consequences of secondary stigma, as a negative and stress-provoking experience for parents (Ainlay et al, 1986; Ben-Yehuda, 1987; Jones et al, 1984), is found to be associated with the child's visible deviating characteristics but also to the distressing reactions of others regarding the circumstances of these reactions (Baxter, 1989). Other studies suggest that the burden of caring for a child with disability along with the stigmatising perceptions about people with disabilities both contribute to parental distress (Green, 2003). Increased emotional distress and social isolation is found to be a typical response among people experiencing secondary stigma (Blum, 1991). Accordingly, Wallace et al (2013) claim that parents are feeling isolated and stigmatised due to people's misjudgement of their child. The negative effect of stigma may be also related to parents' psycho-emotional state: parents with low self-esteem or limited emotional support present a stronger association between the stigma they perceive and the possibility for depressive symptoms (Cantwell et al, 2015). In general, though, stigma impacts parents' psychological status due to decrease of their coping skills and increase of isolation (Cantwell et al, 2015). Social isolation is a frequent consequence of the stigmatising perceptions towards parents, yet it might also concern broader family and friends (Stewart et al, 2017). Marital satisfaction and the social life of parents of children with developmental disabilities have also been found to be affected by the stigmatising perceptions about them (Kwok et al, 2014). Green (2003) describes secondary stigma as a complicated phenomenon, permeating all aspects of the life of a family with a child with disability, even in indirect but pervasive ways. Discussing about the distinction between felt and enacted stigma – where felt indicates the stigma that is felt, namely feelings of shame, and enacted stigma indicates the stigma which is experienced, namely actual discrimination or rejection (Jacoby, 1994; Scambler & Hopkins, 1986) – Gray (2002) suggests that the experience of enacted stigma denotes that the parents have failed to maintain a normal representation of their life, whereas the experience of felt stigma denotes the parents' fear to maintain a normal appearing round of life.

Chan & Lam (2018) suggest the term 'self-stigma', referring to the parents' awareness of the stigmatising perceptions about them and the endorsement of these attitudes into their self-concept. Parents seem to experience a kind of internalization of the stigmatising perceptions, such as disapproval, disparagement and negative opinions of others, to the point that they incorporate them into their self-image, as part of their identity (Chan & Lam, 2017). Therefore, parents might begin to form negative thoughts about themselves, develop feelings of inferiority, consider themselves failures and doubt their parenting skills (Chan & Leung, 2021). This representation of themselves can be accompanied by feelings of shame, social isolation and a tendency to hide their stigmatising identity as parents of children with disabilities. Chan et al (2023) suggest that self-stigma is highly associated with increased parental stress, which has a direct impact to the parent-child interaction, limiting parental warmth and increasing parental hostility. The term has been used before by Mittal et al (2012), highlighting that stigma, namely social stigma, may result in self-stigma through this process of internalization. Self-stigma has been mainly studied concerning parents of children with autism. Additionally, self-stigma inflates the burden experienced by parents, amplifies parental distress but also might impact on the parenting process (Chan et al, 2023).

Literature discusses in general how the consequences of secondary stigma on parents have clear implications for children as well. Children's social interactions are broadly influenced by the stigmatising experiences parents – especially mothers – go through, making the effects of parental stigma multi-generational (Green, 2003). Green (2002) suggests that the parents' stigmatising experiences may convey a high risk for rejection, social isolation, possible maltreatment and loneliness for their children.

Despite how powerful and generalized secondary stigma is, parents do find ways to deal and cope with it. Gray (2002) highlights the attempts of parents to pass as a 'normal' family, refusing the special conditions that their child's disability generate. The 'normalization' of the family's social relations may help parents avoid the stigmatising effects on their family. However, increased interaction with children without disabilities may result in possible further separation, rejection or isolation. Another coping practice that parents seem to adopt is limitation of their social exposure or selective socializing, according to the situation and the behaviour encountered by parents and their children with disabilities (Gray, 2002). This may include selective disclosure (West, 1986), choosing to socialise with friends who show understanding for their child's disability (Birenbaum, 1970) or restricted encounters in public places (Voysey, 1972). However, limited social exposure seems to mainly concern the secondary stigma experienced through interaction. Yet, secondary stigma is not limited to an interactional context but includes all aspects of parents' relationship with their child and of parents' identity (Gray, 2002).

Parents' meaning-making regarding their experience of parenting a child with developmental disability is among the most common reactions of parents towards stigma. Specifically, conceptualizing their parenting experience as positive, emphasizing on strengths or adopting other meaningful roles, namely as a working individual, may protect against stigma (Dagnan & Sandhu, 1999). Mittal et al (2012) point out the parents' development of mindfulness skills and the search for social and practical support, which will help parents reframe their perceptions. Other studies suggest parents' education and emotion management as common coping strategies used by parents in order to handle the stigmatising perceptions within the social context (Green, 2002). Gray (2002) reports the use of humour, the participation in groups for families of children with disabilities and the address to medical and educational services as other coping strategies for parents in order to deal with stigma.

As obvious from this literature review, most researchers until now focus on parents' emotional reactions (discussed in chapters 2.1.2. and 2.2.1) or their interaction within the social sphere regarding their children's disability, namely stigma and secondary stigma. However, each aspect of parents' life is not impermeable and independent from the social milieu. As Gillespie & Cornish (2010) claim, the psychological and social aspect of the individual experience "are more than mere levels of analysis in the social world". This research project aims to examine how the above-mentioned psychological context of parents experiencing their children's disability is situated within the social context and vice-versa. Thus, parents' experience will be approached as a process of psychological change or development but also as a socio-culturally contextualized process, offering a new area of knowledge about raising a child with developmental disability. However, the social context in general and the meaning of stigma particularly is different between social contexts, creating the need for a framed understanding of what is perceived as stigmatising and the processes used by parents to handle these stigmatising socio-cultural challenges within this specific socio-cultural milieu.

2.2.4. Self-related issues of parents of children with developmental disabilities

Parenthood is a determining experience, a transition which is signified by major life changes (Boström et al, 2010). Literature discusses how the development of parental identity is a long-time process, as a result of the experiences, the challenges and the transitions parents go through (Niedbalski, 2021). Thus, becoming a parent of a child with developmental disability involves an enormous transformation on multiple levels. The child's diagnosis influences, tests and ultimately determines the formation and the changes of the parents' identity (Bosteels et al, 2012).

Parenting of children with developmental disabilities may become overwhelming, with the parenting role prevailing over any other aspect of self, to the point that it almost exclusively dominates the parents' meaning on themselves (Todd & Shearn, 1996). Parents describe losing their sense of self when raising children with developmental disabilities (Orsmond et al, 2003). Additionally, the changes in the social context but also in the experience of the social self – namely the experience of stigma, leading to feelings of shame or concern (Gray, 2002) – as well as the development of a sense of "otherness" from the parents (Niedbalski, 2021) may contribute to their social exclusion. However, parents of children with disabilities attempt to reconsider their sense of self, by trying to reconstruct their parental role while experiencing varying challenges throughout parenting. Several aspects of their identity, such as caring for the child, their working status, maintaining a personal and a social life are at risk; parents are requested to achieve a new balance between these aspects of their selves (Beresford et al, 2007).

A key change that parents of children with developmental disabilities experience is the exercise of the caring role. The role of the main carer of the child with disability, especially on younger ages, has been assigned to parents. However, this is a stigmatising role (Cantwell et al, 2015), involving the 'burden' placed on the carer (Morris, 1996), which comes to add up with the negative status of being a parent of a child with disability. This might be related to the fact that caring of children with disabilities if usually not rewarded economically, attributing to caring a socially devalued status. This is reflected by the ambiguous position mothers are found in, lacking recognition and credibility within the professional circles (Ryan & Runswick-Cole, 2008). Parents' role as a carer might also be stigmatising due to the relation literature has assigned between caring and charitable caring, which activates feelings of shame and tragedy (Hughes & Luksetich, 2008). However, this aspect disregards the fact that caring is not only a matter of kindness but also a right (Kittay, 2011). The parent's caring role might prove conflicting with other essential self-roles, namely working, having personal goals or dreams, enjoying leisure time, having social and personal time. This conflict may create a threat or limitation to the parents' sense of self-fulfillment (Niedbalski, 2021)

The identity of the carer within the family dynamics includes a gender dimension, as carers especially of children with disabilities are mostly mothers. Skeggs & Creese (1998) suggests that caring is integrated into women's role in society, providing an aspect of recognition and appreciation into their identity. Additionally, mothers develop their identity as main child carers, since it is considered less socially acceptable to let care to fathers or others within or outside the narrow family (Baldwin & Twigg, 1991). According to Ryan & Runswick-Cole (2008) mothers of children with disabilities often find themselves in an extended and expanding caring role, as a consequence of which, mothers frequently encounter limitations in engaging in additional roles apart from the primary responsibility of caring for their child. Finch and Mason (1993) argue about the establishment of mothers' role as dominant carer of children with developmental disabilities, a role which is deeply entrenched and difficult to change: "*People's identities are being constructed, confirmed and reconstructed – identities as a reliable son, a generous mother, a caring sister or whatever it might be ... If the image of a 'caring sister' is valued as part of someone's identity then it eventually becomes too expensive to withdraw from those commitments through which that identity is expressed and confirmed*" (Finch and Mason, 1993; p. 170). However, the mother's role as a carer usually constitutes a sacrifice and involves full time, permanent care of the child (McLaughlin et al, 2008).

Cronin (2018) suggests that mothers of children with disabilities adopt a "special identity", exercising their caring role significantly unconditionally and more selflessly, essentially differentiating them from fathers but also from parents of children without disabilities (Shearn & Todd, 2000). This gender difference is also obvious in terms of employment as well, with fathers' employment being more broadly socially accepted than mothers (Niedbalski, 2021). In the same perspective, mothers of children with disabilities describe that their return to work must be due to economic reasons and not personal or career goals (Lewis et al, 1999). Literature reports that mothers usually experience feelings of guilt and anxiety when leaving their children (Niedbalski, 2021), a condition which is greatly associated with their caring role.

Gilligan (1987) however, points to the fact that caring can contribute to a positive side of identity, an identity more socially contextualized and away from approaching the carer as a tool. Thus, the woman's role in caring can be understood as a resource of fulfilling a positive sense of self and a way of challenging the individuality of the carer's role within the social context, instead of understanding it as restricting to woman's identity. According to Ryan & Runswick-Cole (2008), mothers raising children with disabilities can extend their caring role to encompass wider societal or community issues, integrating disability-related public work to their caring role and finding, as a consequence, the caring experience to be rewarding and enriching. The caring role offer mothers a new sense of self, through the development of new meaning about themselves while experiencing this identity (McLaughlin et al, 2008). In that sense, caring is represented as a role which determines one's identity, by defining the life of the carer (McLaughlin et al, 2008). Caring seems to result in parents' losing aspects of their identity but at the same time to recreate other aspects of their identity, equally defining to their selves (Beresford et al, 2007).

An aspect of the parents' identity, broadly impacted by their children's disability, is their social self. Disability creates new circumstances in the family but also in the social context.

Sometimes parents struggle with the interactional aspect of their child's disability, which in turn impacts upon their identity (Boström, 2010). According to Shakespeare (in Barnes & Mercer, 1996) disability provides a negative identity for the person with disability within the social context. Correspondingly, parents of people with disabilities, stigmatised by their association with their children, acquire a negative identity. Gray (2002), discussing Goffman's work on stigma, describes the identity of the secondary stigmatised person as the "success or failure of the individual in maintaining a 'normal' identity" (p. 737). The development of an identity other than normal might be experienced as an undesirable or a disparaging experience or even as a failure. Niedbalski (2021) discusses about the parents' sense of being negatively different, as a critical aspect of parenting a child with developmental disability: acknowledging the "otherness" contributes in underestimating their identity and in developing a negative sense of self.

Change following critical life events might be experienced as a threat, with identity negotiation being a way to adapt to this change (Deaux & Ethier, 1998). Identity transformation allows the individual to reconsider him/herself in relation to others but also in relation to any new social context (Brett, 1984). Denial, enhancement or alteration of existing identities are included in the negotiation, aiming at their restriction, improvement or review. In that case, parents negotiate their identity to respond to the stressful event of their child's disability.

However, literature reports that experiencing change after a critical and traumatic life incidence might also have positive outcomes, with people reporting benefits out of the stressful event (Barnard, 1994). Newman (1994) suggests the theory of expanded consciousness: the experience of a tough life incidence might make people realize the ineffectiveness of previous ways of thinking and acting, leading to imbalance and insecurity. This uncertainty proves productive for the individual, who is activated to search for new ways of thinking and acting, in order to replace the old ones. The individual is redefined through this new way of approaching oneself and the world, developing a new sense of self and experiencing transformation, a process which was described as "expanding consciousness". The transformation signifies an improved sense of self, meaning and personal agency of the individual.

Parents of children with developmental disabilities have experienced the major life event of their child's diagnosis. Literature suggests that this experience is highly transformative for parents, a kind of transcendence of their sense of selves (Green, 2002), leading to profound personal changes. Scorgie et al (2004) introduce the working model of the three processes, which parents' experience during their identity transformation: answering emerging questions related to their child's diagnosis – questions reflecting their meaning making (i.e. why did this happen), their image making (i.e. who is my child) and their decision making (what will I do) – and processing these answers, allow them to move forward and to experience transformation of self and perspective. Parents go through an adaptation process, in which they are actively involved (Nota et al, 2004), with control and self-agency being in the core of this process of transformation. Parents' experience of transformation is an ongoing process, highly related with the experienced stress and strongly affected by external influences (Scorgie et al, 2004). According to Scorgie et al (1996), the transformation of parents of children with developmental disabilities might concern changes in self-identity (personal transformation), changes in interacting with others (relational transformation) and changes in the parents' perspective (perspectival transformation).

Overall, literature suggests that parents often struggle with the new circumstances that disability creates in the family but also within the broader social milieu, which in turn impacts upon their identity (Boström et al, 2010). What is not discussed in existing literature, though, is how parents' meaning-making regarding their child's disability influences parents' identity. This research project specifically explores how the parental identity is determined or changed after the diagnosis of their children with intellectual disabilities. What are the processes through which this change takes place?

Additionally, parents of children with disabilities seem to adopt multiple identities (McLaughlin et al, 2008). Research emphasizes the function of multiple identities as a protective factor (Perkins et al, 2002) and their role as a protective shield against psychological distress. Multiple identities might function as the balancing factor and minimize the effect of a problematic existing identity (Thoits, 1988). The literature does not examine whether and how parents of children with disabilities adopt multiple identities, and how these multiple identities help them cope through their experience parenting their children with developmental disabilities. This research project intends to explore the real impact of parents' multiple identities and how the new conditions affect their parental identities.

Lastly, what is not clear from the existing research on parents experiencing their children disability is how their identity transformation takes place. Generally, the transformation process seems to be related with positive outcomes and effective ways of coping for parents raising children with developmental disabilities. However, a question not answered yet is how this transformation is influenced by the meaning parents construct about their experience. Besides, the process of transformation is definitely impacted from the several societal influences, which is another area not adequately examined. This study aims to explore some of the self-issues that parents have to deal with as they experience their transition to parenting a child with developmental disability. These self-changes as I will show are mediated by the social context in which parents are positioned.

Chapter 3: Theoretical background

This chapter aims to describe the theoretical background underpinning this study. In the first part of it, I explain the broader epistemological considerations of the present study, which constitutes the larger framework for perceiving the parents’ experience, namely phenomenology and social constructivism. In the second part, I analyse the more specific theoretical approaches, with which the data of this research can be analyzed: Social Representations Theory and Symbolic Resources Theory. For each of these theories I elucidate how it will contribute to the study of the parents' experience raising children with developmental disabilities.

3.1. Epistemological considerations

Epistemology deals with how knowledge is produced (Bonjour, 2002; Dancy, 1985). The different approaches to knowledge also determine the way we "read" and analyse the topic of a research. In this particular study, phenomenology and social constructivism will be used as a broader framework in order to understand the experience of parents raising their children with developmental disabilities.

3.1.1. Phenomenology

3.1.1.1. Understanding phenomenology

The phenomenological approach in psychology focuses on *the study of phenomena as they appear* in one’s consciousness and on the description and analysis of how these phenomena are experienced by individuals (Leahey, 2001). It seeks to understand the subjective experience by analyzing the narratives – written or spoken – of individuals, examining their subjective perspective (Lester, 1999). Therefore, phenomenology aims to examine “subjective meanings and individual sense attributions” (Flick et al, 2000; p. 5).

Phenomenology suggests that the best way to uncover and explore a phenomenon is to make a careful description of what is seen. The description is based on the individual's experience and intuition and not on a theoretical framework based on specific assumptions about the human psyche.

The philosophical origins of phenomenology are found in the work of Edmund Husserl (1859–1938), who is known as the founder of phenomenology (Spiegelberg, 1994). His emphasis stands on the study of phenomena as they are directly experienced by individuals and the intricate nuances of human subjective experiences without preconceived notions or theoretical biases (Husserl, 1970).

The phenomenological approach was introduced as a response to positivism. According to the Cartesian principles of Descartes, there is a strong distinction between the outer reality and the individual experience of reality, with the former one being only understood in rational terms through cognitive processes of deduction (Moran, 2002). The disciplines of psychology, developed until then, followed the methodology of the natural sciences (Englander & Morley, 2021). According to Giorgi (1970), by imitating the methodology of natural science, psychology abandoned the study of human beings "as persons". On the contrary, phenomenology focuses on providing detailed qualitative descriptions of individual first-hand experiences, differing from quantitative methods which aim to quantify and predict behaviour (Langdridge, 2007). Inspired by Husserl's call to return to direct experience, phenomenology evades the study of underpinning causes and emphasizes the clear descriptions of phenomena (Stanghellini et al, 2019). In terms of the outside world, phenomenology seeks to understand the outer reality as it is interpreted and through human consciousness (Zahavi, 2003).

The idea of *life-world* is central in phenomenology. It refers to the subjective world of everyday experience, the world as it is directly and immediately experienced by individuals (Schutz, 1972). It encompasses the totality of experiences, perceptions, feelings and meaning that consist an individual's lived experience. The life-world is the background or the context within which all experiences and interactions of the individual take place. The concept of life-world emphasized the idea that experiences are not isolated or disconnected but are instead part of a continuous and interconnected field of life. Within the life-world, individuals navigate various experiences, interact with others and make sense of their surroundings. Understanding the life-world is essential for exploring human consciousness and gaining insight into the ways people perceive and interpret the world around them (Eberle, 2014; Husserl, 1983).

In phenomenological approach, the concept of "experience" holds a considerably more intricate meaning than its everyday interpretation suggests. Experience or being is understood as being in relation to a phenomenon, as a phenomenon intricately tied to relationships, characterized by qualities such as directedness, embodiment and awareness of the world. This understanding of experience is captured by the term “being-in-the-world” (Langdridge, 2007). According to Heidegger (1962), the interpretation of an experience is done by relating it to the relevant features of its context, by focusing on the lived experience of the individual, emphasizing the search for meaning in one’s existence where person and world are mutually constitutive, namely their ‘being-in-the-world’ (Davidsen, 2013). This ‘being-in-the-world’ emphasizes the positioning of the experience in the social field, thus the experience as profoundly embedded in the social context.

Examining the lived experience of a phenomenon allows us to grasp its significance and understand its contextual dependence. However, qualitative research does not approach these lived experiences as empirical entities, to be studied in isolation, but exploring the relationship between lived experiences and phenomena within a specific context, without any attempt to empirically generalize the lived experiences themselves (Englander, 2019).

3.1.1.2. The parents' experience through the perspective of phenomenology

As described, phenomenology emphasizes the exploration and understanding of lived experiences from the perspective of those experiencing them. It seeks to capture the essence of human consciousness, feelings and perceptions, offering rich and detailed qualitative insights into various psychological phenomena (Smith, 2018), revealing the quality of first-person experiences (Langdridge, 2007).

Accordingly, I approach the parents’ experience phenomenologically, as I am interested to examine the quality of their experience parenting their children with developmental disabilities and the way they themselves define this experience. Particularly, phenomenology allows a profound exploration of the parents’ subjective experience, by focusing on their lived experiences, including the deep investigation of all intricate aspects of their experience, such as emotions, challenges, perceptions, which might be overlooked by other methodologies. Since phenomenology is the study of phenomena as they appear in one’s experiences, my interest is to capture the ways parents experience their parenting experience and the meanings this “phenomenon” has in their experience. According to Giorgi & Aanstoos (1985, p. 1), the purpose of the phenomenological research is the “direct analysis of the psychological meaning of naive descriptions of personal experiences provided by individuals from all walks of life in situations that are easily recognizable as belonging to everyday life”, which reflects in detail my aim for this study.

Additionally, I am interested to explore the meaning of the parents’ experience as context dependent. According to Heidegger, individuals and their experiences are always ‘in the world’, namely their ‘being-in-the-world’, indicating the need to interpret these experiences and the meaning they hold by examining their contextual relations of these experiences in the world. The way one is related to things (or experiences or phenomena) is the point where phenomenology reveals their situation in a context of equipment and in being-with-others (Heidegger, 1982). the phenomenological approach is the appropriate methodology to explore the understanding of human experiences and the nature of their reality, by embracing the depth and complexity of individual experiences. By following a phenomenological theory of science, I do not make empirical generalizations about a phenomenon under study – the parents' experience of raising their children with developmental disabilities in this study – but I analyse the meaning of this phenomenon as it appears within a given context (Englander, 2019). The context in phenomenology is the world as a natural setting, as the field of the thoughts and all the explicit perceptions of the individuals participating in my study, who live their experiences within this world (Merleau-Ponty & Smith, 1962). I am interested to explore the meaning of experience within the specific context of this experience, as it is seen and experienced by the individuals, thus by parents. With the use of the social constructivist approach, I am interested to examine the parents' meaning as it is constructed, and mainly co-constituted, within with specific context.

Finally, phenomenology approaches a phenomenon in relation to the interest of its observer, since "a situation is always perceived actively in phenomenology as something correlated with an interest carried out in a specific attitude" (Luft, 1998; p. 157). The observer, namely the researcher, is requested to reach a deep sense of understanding and connection with the experience of the individuals' asked, namely the parents, by subjectively analyzing the experience and the underlying thoughts and the feelings expressed through their narratives (Lester et al, 1999). Phenomenology offers, among others, a comprehensive understanding in order to approach the parents' experience, as it goes beyond observation, allowing for an in-depth exploration of thoughts, feelings and context of the experience. This holistic understanding is crucial when dealing with complex and emotionally charged phenomena, such as parenting children with developmental disabilities, enabling the researcher to examine all multifaceted aspects of the parents' experience.

In summary, the phenomenological approach offers a profound and deep exploration of the lived experiences of parents raising children with developmental disabilities.

3.1.2. Social constructivism

3.1.2.1. Understanding social constructivism

Constructivism represents an epistemological position based on the central concept that "reality is constructed by the observer and is not an external entity entirely separate from the observer" (Gallant, 1993, p. 119). In other words, reality is constructed through a person's active experience of it. Human experience, including individual perception, is historically, culturally and socially mediated (Berger & Luckmann, 1966). There is not one single truth or knowledge but truths and pieces of knowledge, concerned with recognizing the different ways of constructing social reality available in culture. From a constructivist perspective, any person's perception or construction is as 'true' as any other person's perception or construction, as long as it works within a particular context (Dickerson & Zimmerman, 1996).

In contrast to positivism, where the aim of research is to produce objective knowledge (Larrain, 1979), and empiricism, where the knowledge of the world arises from the stimuli of the individual's experience (Psillos & Curd, 2008), *social* constructivism deals with knowledge as a set of beliefs or perceptual patterns people use in order to interpret actions and phenomena in the world. According to social constructivism, people's construction of knowledge involves developing perspectives to comprehend the world. These perspectives, representing a subset of possible understandings, shape people's conceptualization of how the world can be perceived (Jackson, 2010). Therefore, the distinction between the conception of the external world and the responses of the individuals to the external world stimuli is not clear or clearly perceptible (Bruner, 2018).

Social constructivism suggests that what may appear as a naturally occurring social phenomenon is, in fact, socially and culturally built. There is not given reality but reality is constructed intersubjectively, representing the individual needs and behaviours, the accepted standards and the underlying assumptions of the culture the individual lives and the limitations imposed by the established society reflecting the culture where the individual lives (Bruner, 2018). This socially constructed reality is constructed by individuals within social groups over periods of time, mainly through conversation – thus the use of language – and social rituals, which serve as means to link the personal perception of different individuals (Jackson, 2010). In other words, knowledge is actively constructed through social interaction, languages and people's shared experiences.

A profound concept in social constructivism is the *socio-cultural context*, as ideas do not exist in vacuum, they inhabit in a social setting (Doise, 1989). This context is exactly where the idea, the phenomenon, the reality or else, is formed. Social constructivism focuses on the significance of the socio-cultural context in shaping individual understanding and knowledge. Cultural norms, values and social practices impact on how people interpret information and construct their meaning on social reality (Berger & Luckmann, 1966; Doise, 1989).

For social constructivism, *language and communication* play also a critical role (Gergen, 1987; Flick et al, 2000). Language is considered to be a key tool in the construction of knowledge from a social constructivistic perspective (Gergen, 1994; Rogoff, 1990). Through language and communication individuals share and negotiate meanings. As a vital component of social interaction and a significant element of socio-cultural context, language is represented as crucial in shaping individual's understanding and learning (Jackson, 2010; O'Leary & Wright, 2005).

Social constructivism has a rich history, with the first ideas being developed during the Enlightenment and its contemporary roots being found in the work of the sociologists George Mead and Emile Durkheim (Taylor, 2014). However, the term social constructivism was attributed to Berger & Luckmann, for their work "The social construction of reality. A treatise in the sociology of knowledge" (1966), where they consider and juxtapose the objective reality of society and the emerging subjective consciousness of society.

In literature the term social constructionism is also quite often encountered. Although based on the same central idea that knowledge and reality are socially constructed, social constructionism focuses on the processes of social interaction in the production of knowledge rather than the outcome of the socially constructed reality, namely the social constructs (Gergen, 1985).

Social constructivism has been used within several disciplines, apart from the epistemological field, such as sociology, psychology, philosophy, neurobiology, psychiatry, information science and education, both in practice and in academic research as well (Flick et al, 2000; Marshall, 1996; Lapadat, 1997; Prawat, 2000). Additionally, several approaches to constructivism seem to have been developed, such as critical, cultural, genetic or radical (Lapadat, 1997; Marshall, 1996; Prawat, 2000). Finally, it is interested to note that social constructivism has been used to explore a wide range of topics, such as health and illness (Gawatz & Nowak, 1993; Lachmund & Stollberg, 1992), education and learning (Knapp et al, 2019; Stabile & Ershler, 2016), issues of technological change (Flick, 1996), socialization (Grundmann, 1999) and more.

3.1.2.2. The parents' experience through the perspective of social constructivism

This study explores the parents' experience raising their children with developmental disabilities, through the perspective of social constructivism. Social constructivism is considered to be a suitable lens to approach this topic, as an epistemological framework suggesting that knowledge and understanding are constructed within the social context, embracing cultural influences, social interaction and interpersonal relationships in shaping individuals' perception and interpretation of their experiences. In the following lines, I discuss the advantages of using the perspective of social constructivism to study the experience of parents' raising children with developmental disabilities.

Primarily, social constructivism allows to explore the *subjective nature* on their parents' experience, emphasizing on their *meaning making* on the parenting experience. According to social constructivism, individuals actively construct their own understanding of the world, based on their distinct experiences and perspectives (Gergen, 1985). This particular knowledge construction and people's meaning making processes are considered to be the focus of social constructivism traditionally (Stabile & Ershler, 2016), which is also the emphasis of this research project. Piaget referred to the subjects of this process as unique constructors of knowledge and as epistemic knowing agents (Kohlberg, 1968). Parents are, accordingly, approached as "knowing agents", asking them to allow my exploration on their captivating and critical parenting journey. Additionally, social constructivism highlights the different ways in which individuals are capable of comprehending and getting to know the world: "the experience of anything out there is validated in a special way by the human structure which makes possible 'the thing' that arises in the description … every act of knowing brings forth a world" (Maturana & Varela, 1987, p. 25–6). The aim of this research project is to reveal this unique world of the parents' experience of raising their children with developmental disabilities.

Approaching the parents' experience in social constructivistic terms also enables the understanding of their experience within the *social-cultural context*, by which it is decisively influenced. Social constructivism highlights the impact of cultural and social norms on individuals' perceptions and interpretations (O'Leary & Wright, 2005; Gergen, 1985; Flick et al, 2000). The contextual factors, such as the social environment, the historical background or the cultural standards and values shape the way individuals interpret information and construct knowledge. Stabile & Ershler (2016) claim that knowledge cannot be separated from the context, existing within the situation, embedded in individuals' activity, intertwined with their culture and language across physical and social space and time. Respectively, I aim to consider the context in which the parents' learning and knowledge construction occur, a contextual understanding of the parents' experience, along with the effects of the broader and the closer social and cultural milieu of their experience. This context may involve social representations of developmental disability, of the ideal child, or more practical factors, such as institutional support for parents of disabled children.

Part of the socio-cultural context is *social interaction and relationships*, the role of which is also underlined in social constructivism as contributing to the individual's process of knowledge. Social constructivism suggests that knowledge cannot exist independently of human interaction, as knowledge is socially constructed, thus individuals make meaning through these interactions with others and the world around them (McKinley, 2015; Gergen, 1985). Studying parents' experiences through a social constructivistic perspective will permit to explore how interactions and relationships – with their close and broad family, with professionals, with other parents – and social attitudes contribute to the construction of knowledge and understanding regarding their experience of raising children with developmental disabilities. Another important aspect – or better outcome – of social interaction is the shared knowledge, which role social constructivism pinpoints as individuals create shared knowledge, namely social constructs, that represent a collective rather than an individual understanding of the world (Jackson, 2010). In the context of parenting children with developmental disabilities, understanding how parents share information, support each other and collectively construct knowledge can provide a valuable insight into the meaning of their experience.

To conclude, using the social constructivistic perspective in order to study the experience of parenting children with developmental disabilities, allows for a deep exploration of the parents' subjective, social-cultural and interpersonal nature of this experience. This perspective facilitates a more comprehensive understanding of all complex aspects, including interactions, shared knowledge or else, that shapes parents' knowledge and perception about their parenting experience.

3.2. Theoretical considerations

The experience of parents raising their children with developmental disabilities will be approached through the prism of the Social Representations Theory and the Symbolic Resources Theory. Both theories reflect the epistemological basis of social constructivism.

3.2.1. Social Representations Theory

3.2.1.1. Understanding Social Representations Theory

Social Representations Theory attempts to locate psychological activities in social life (Duveen & Lloyd, 1990). Moscovici introduced social representations, claiming that "the representation is an organized body of knowledge" (Moscovici & Lage, 1976; p. 27). According to him (Moscovici, 1984) social representations are identified as a system of values, ideas and practices that allow people to empirically name and comprehend the world, themselves and culture. In other words, social representations are attributions that summarize and condense multiple meanings, allowing individuals to interpret reality and position themselves in the social world (Jodelet, 1991; Howarth, 2006).

Social representations are active and purposeful (Moscovici & Marková, 1998). Their aim is to turn the strange into familiar and the invisible into visible: in order to manage to understand the unknown, individuals need to have a cognitive category to include it and become familiar with it (Mantoglou & Papastamou, 1995). Specifically, social representations implement a dual function: firstly, to establish an order which will enable individuals to orient themselves in their material and social world and to master it; and, secondly, to enable communication among the members of a community by providing them with a code for social exchange and a code for naming and classifying unambiguously the various aspects of their world and their individual and group history (Moscovici & Néve, 1973). Consequently, any social or other object is converted into a social reality due to the fact that a group of people adopts and uses a certain representation of this object, which makes it part of the social world of this group.

Moscovici described the processes that social representations are constructed and transformed, through *anchoring and objectification*. Anchoring refers to the function where "the unfamiliar or remote is absorbed into the familiar categories of everyday cognition", reflecting the process of connecting new information and experiences to pre-existing cognitive structures or mental frameworks within a social group. Objectification denotes the function where “representations are projected into the world, so that what was abstract is transformed into something concrete” (Duveen & Lloyd, 2013, p. 174), reflecting the transformation of abstract or complex ideas into tangible and perceptible ones, making them more easily understood and shared within a social group. Both functions are complementary and interdependent, contributing to the construction and maintenance of shared meanings, facilitating communication and understanding among group members, while limiting the perceived threat of ‘unfamiliar objects’ (Duveen & Lloyd, 2013; Moscovici & Halls, 1993).

Disability has mainly been represented in literature as a negative concept. Shakespeare (2013) discusses the representation of people with disabilities as objects, being objectified as passive, freaks and non-humans and as receivers of pity and charities. People without disabilities are found to project their concerns about death, physicality and mortality on people with disabilities, representing on them all these difficult aspects of human existence (Longmore, 1987). Morris & Morris (1989; p. 62) claims that “the norm is measured by the absence of disability” and those not representing what is considered as normal, in terms of function, appearance, or behaviour, they fail to conform, being therefore “the other”. This aligns with the representation of people with disabilities as not worth living, which was very powerful and well reflected in Europe of the ‘30s (Morris & Morris, 1989). In recent years, media plays a crucial role in shaping social representations, often portraying disability through a lens of pity or inspiration (Hall, 2010). Young (2014) claims that disability has been socially represented as a bad thing and disabled people are objectified as inspirational figures for the benefit of non-disabled people. The shared concept in the above-mentioned social representations of disability is reflected in the concept of Moscovici about otherness (1994), where the non-normal person – namely mentally ill, disabled or else – is represented as different from the self, as other than the self, which is represented as normal.

3.2.1.2. Using social representations to approach the parents’ experience

In order to approach, analyse and understand the parents’ experience, I use the Theory of Social Representations. Parenting a child with developmental disabilities suggests becoming part of a new reality with strong social implications for parents. Into this new reality, parents have to encounter different types of meanings and social representations that the society holds about people with disabilities. Most of these representations are negative, including general beliefs of people with disabilities as passive, not normal and not able to decide about themselves (Kriegel, 1987). Relative attributions about families of people with disabilities are also formed, focusing on pity and representing families as burdens (McLaughlin, 2012). Social Representations Theory allows to examine how all these ideas permeate parents' experience in the particular social context and become part of their new reality.

Social Representations Theory is also expected to help explore parents' self-related issues. In case of parents of children with developmental disabilities, social representations about parenting and disability are found to be critical in the parents' formation and process of their self-issues. Both groups – of parents and of people with disabilities – apply a distinct membership to parents, creating representations that permeate their daily interactions. Social Representations Theory enables the exploration of these representations and how they impact parents' self.

3.2.2. Symbolic Resources Theory

3.2.2.1. Understanding Symbolic Resources Theory

According to Valsiner (1987), the individual and the social are mutually created. Human actions, emotions and thoughts take place within a particular social context, from which they are actively influenced. The theoretical framework of Symbolic Resources Theory (Zittoun, 2006) approaches psychological processes considering the individual's socio-cultural context. Symbolic Resources Theory focuses on issues of psychological development and change, exploring how people use cultural and symbolic resources in order to create meaning and cope during periods of change. Change starts with a rupture, which is discussed in the next section.

Understanding ruptures

A rupture is a disruption in the regular flow of a person's life, a determinant change experienced by a person as a discontinuity in the standard course of ordinary life (Zittoun et al, 2003). Zittoun (2004) describes ruptures as events that put at stake certain routines or taken-for-granted situations. For example, Zittoun (2004) discusses the use of symbolic resources by parents experiencing their transition to parenthood, while examining the parents' choice of name for their coming children. The rupture is the beginning of a process of repositioning in order to build new understanding towards the world and personal redefinition (Zittoun, 2004).

Ruptures are distinguished according to their cause. First of all, ruptures may follow *intra-personal changes*, like getting older or changing beliefs. *Changes of the person's relationships* with others, like cheating within a couple or a conflict with parents, may also result in a rupture. The origin of a rupture may also be found on a *change of the immediate environment* of the person, as a significant person's loss or a family member severe health problem. Ruptures may also be the outcome of *large-scale changes* in the person's socio-cultural context, like a war or an earthquake (Zittoun, 2004 & 2006). Types of ruptures, also, originate regarding who they affect, as ruptures may be collective or individual. Thus, a rupture may influence a group of people – like a state's financial crisis – or a single individual – like a person's unemployment. However, a collective rupture may maintain a special individual meaning (Zittoun, 2008). For example, the collective rupture of the financial crisis may work positively for an individual who decides to return back to her roots and grow her family land. These rupture categorisations are not always clearly distinct in people's lives or may be interconnected (Zittoun, 2004 & 2006).

Ruptures are qualified with several degrees of generality (Zittoun, 2006). There are ruptures that affect abstract beliefs held by a person, like believing in a religion. However, other ruptures influence a person's single action, like starting a new hobby. The degree of generality, though, is proportional with the aspects of life this rupture affects. For example, the adoption of punk movement may influence many aspects of an individual's life, including ideology, way of dressing, forms of expression, dance, preferred literature, cinema and – of course – music. Ruptures can also vary in terms of their time-extension (Zittoun, 2006). Some ruptures may be sudden and experienced as so, for example a person's job loss. Other ruptures may be slow and recurrent, something that influences the way a person feels and reacts on that rupture, by using for instance defencing mechanisms. A chronic disease is a typical example of a slow and recurrent rupture, which affects one's life on a daily basis. Ruptures may, in addition, affect several spheres of the individual experience. As Zittoun claims (2006), each individual is involved in various fields of activity separating their life accordingly. Therefore, our life is usually a total of many experiences like personal, social, professional, family life, belief system and so on. A rupture may influence only one, some or all of those micro-worlds. However, a rupture definitely affects a person's current sphere or spheres of experience.

Simão (2003) describes ruptures as disquieting experiences. In fact, ruptures generate imbalance as moving from the previous state of certainty to the unknown, following the rupture, state of uncertainty. Zittoun (2007, p.4) adequately defines uncertainty as "a person's experience of blurred personal reality, relatively to a previous state of apprehension of things". According to Abbey and Valsiner (2005), the change between the known and the unknown brings ambivalence.

Uncertainty is a main characteristic in *human development*. As Abbey and Valsiner (2005) claim, all development is necessarily based on uncertainty between what has already developed and what could develop in the next time moment. They adequately describe this condition as the "awkward dance of adapting to the present while dealing with various possibilities (uncertainty) of the future" (Abbey & Valsiner, 2005: paragraph 5). The effort of integrating the future in the past-to-present coerces the individual to plan for the next moment's experiences (Valsiner, 2007). Thus, the person asks to find a pathway through uncertainty towards a new regularity using previous skills and knowledge in order to generate new ways of thinking or acting (Zittoun, 2004). This step forward is achieved through meaning-making. Hence, uncertainty of human development helps the individual to constantly adapt to the present and prepare for the immediate and unknown future by creating subjective stability, namely engage in new ways of thinking (meaning-making) and acting.

This process of activating relevant skills and creating meaning to cope with the new situation is described as period of transition. Zittoun et al (2003) defines transition as the processes which aim at reducing uncertainty. Overall, ruptures are followed by a period of transition, during which individuals question previous understanding and consider reconstruction.

Understanding transitions

According to Zittoun (2006) transitions are periods following ruptures, during which people develop new identities, new skills and apply meanings to their trajectory and their world. Therefore, transitions constitute balancing processes triggered by ruptures and aim at reorganizing and dealing with the previously experienced uncertainty. Zittoun (2006) examines the youth as a period including multiple transitions, regarding identity, social roles and social environment. Transitions are, undoubtedly, periods of change from one state or condition to another, where individuals try to connect past (including the uncertainty of a rupture) with the future, to help progress from one life stage to the next but also to support their relationship with their own world. Transitions may refer to personal situations, such as the transition to adulthood, or can also follow broader societal events, such as a physical disaster (Zittoun et al, 2003).

The concept of transition is not new. Psychological change has been encountered in Piaget's theory of cognitive child development. According to Piaget, cognitive development involves adaptation processes which enable transition from one stage of development to another. Children, ordinarily, use existing schemas to deal with a new object or situation, in order to construct an understanding of the world around them. When a child is able to deal with most new information through this process of assimilation, equilibrium has been achieved (Piaget & Cook, 1952). Transition was also previously depicted by Dewey (1922) as conflict. Examining disharmony in human nature, Dewey regarded conflict as the key ingredient of reflection and ingenuity. Conflict makes necessary functions emerge for individual's thought, such as observation, memory, invention and activation. The ultimate goal is to discover intervening terms to harmonize difficulties and maintain congruity. Conflict promotes progress through arousing intelligence, substituting the arbitration of mind with friction, contrast and collision.

Current literature has also been engaged with the study of transitions. Valsiner (1997) notes that the individual's needs to reduce uncertainty and anxiety designates the period of transition, where psychological work takes place towards the goal of adjusting to the new situation. Abbey & Valsiner (2005) point out the ambivalence between individual and environment emerged from the need to cope with uncertainty; adaptation comes with the individual's ability to create symbolic meaning, allowing to consider the consequence of future actions before engaging in them. Developmental transition is the main focus of Zittoun's work, exploring the transition to parenthood (2004) and the transition during period of youth (2006).

The unit rupture – transition

As described above, transitions consist of processes towards a new balance. The necessity for balance is triggered by the uncertainty encountered due to experiencing a rupture. This is the reason why Zittoun (2006) defines rupture-transition as a unit of analysis for studying psychological change. In other words, the uncertainty and imbalance of rupture needs to be reorganized and dealt with, and the reorganizational process is identified as a transition.

During transitions, individuals recreate meanings, define themselves in new ways and activate relevant skills to help them cope with the new situation (Kadianaki, 2010).

Zittoun (2004) aptly describes transitions as a window on processes of change at the level of skill acquisition, identities, but also meaning construction. Specifically, there are three core types of changes ruling the transition. First of all, is the *reconstruction of identities*, including the repositioning and relocation of the individual; this reconstruction involves the use of past as well as future representations of the self at a given socio-cultural location. A second type of change is that of developing and gaining new *skills and knowledge* in the level of social, practical and theoretical aspects of life, which allow new ways of action, communication and behaviour. To do so, the individual needs to construct personal *meaning* about the transition but also about the connection of transition to his whole life, so as to move forward. These changes allow the person to carry on, to orient towards the world and, at times, to achieve development. Zittoun (2004) defines a transition as developmental when the individual is ready to leave her previous state and, using the skills and knowledge acquired until then, create new ways of thinking and acting, in order to get organised in the presence of uncertainty and form new states of regularity. Transitions are, thus, necessary conditions for development; but not always leading to psychological development.

Transitions are considered successful and fully complete when two basic balancing conditions are fulfilled. Firstly, the employment of a previously useful tool – a skill or knowledge – after being transformed and recomposed, used in a radical new way. Secondly, the success of transition is obvious when maintaining a sense of being the same through change, when a flexible balance of change has been achieved, between maintaining past and creating newness. Therefore, the future, new state of regularity, intended in transitions, is also a part of the present. Abbey and Valsiner (2005) argue that the present is interestingly influenced by the future, as any anticipation of the future is not itself in that future, but in the move towards it. Accordingly, the transformation of uncertainty into a new form of stability is accomplished during transition, maintaining important past elements and, at the same time, enabling newness; building something new without alienating the individual from her past (Zittoun, 2004). This integration of the future in the past-to-present entails the use of symbolic elements as resources (Abbey & Valsiner, 2005).

Understanding symbolic resources

The uncertainty of ruptures

Symbolic resources are cultural resources of symbolic quality (Kadianaki, 2010). Zittoun (2004) defines symbolic resources as cultural elements employed for thinking, action and development. Specifically, she argues that symbolic resources are those cultural elements "mobilized by a person in a situation not related to the situation of their internalization, and which the person uses as means in order to do something" (Zittoun 2004, p. 133). In other words, cultural elements, when used in order to do something – to cope, to modify or to influence – are transformed into tools, into means for this action. Thus, cultural elements become instruments – symbolic resources – to emphasize the active role of the individual. Zittoun accurately describes symbolic recourses as cultural elements drawn from the symbolic stream to be used by someone to achieve something (Zittoun et al, 2003; Zittoun, 2006).

Symbolic resources and signs are not identical. Signs are socio-culturally contextualized cultural elements, whereas symbolic resources are socio-culturally contextualized cultural elements carrying personal meaning for the user. Therefore, symbolic resources are carriers of socially encoded cultural meaning made up by persons (Zittoun, 2006). Holy Bible, for example, is a cultural element, a sign carrying semiotic meaning derived from the socio-cultural context in which it is found; the same cultural element confers personal meaning to a religious person and different personal meaning to a priest, where is encountered as a symbolic resource. Consequently, it is the personal significance that turns a cultural element into a symbolic resource.

This "transformation" of a cultural element into a symbolic resource is feasible through processes of interiority. These processes of interiority involve the ways through which a person thinks, learns and experiences various meanings and their related feelings. Individuals are able to internalize and memorize cultural elements, so as to turn them from elements of the social world into individual resources (Zittoun, 2004). Symbolic resources, thus, constitute the changing point of "a socially shared element into a psychologically relevant resource", an individual link "between inner world and socially shared reality" (Zittoun, 2007; p. 345).

Cultural elements considered as symbolic resources are determined by three essential conditions (Zittoun, 2006). Firstly, the cultural element should be intentionally used for a specific need and objective (Valsiner, 1998), that is for example to feel better. Second condition for cultural elements to be considered symbolic resources is the fact that they enable people to have strong imaginary experiences, which allow impact on individual's direct experience (Harris, 2000), that is for example reading poetry. Lastly, the cultural element should be something concrete and materially bound, that is for example a theatrical play. Symbolic resources have been also categorized according to the type of cultural element they stem from. Zittoun (2006) claims that symbolic resources might be specific cultural elements, like books, music, art, etc; or symbolic systems, like religion, beliefs, political movements, etc. Kadianaki (2010) suggests that people also use symbolic resources which may not necessarily have material existence, such as a religious system.

The use of symbolic resources

Cultural elements are turned into symbolic resources to support the psychological work of transitions (Zittoun, 2006). Specifically, symbolic resources are conceptualized to facilitate the creation of new meanings and actions in periods of change. Thus, the use of symbolic resources mediates change; they are cultural tools, used as representational acts, to enable acting and thinking. It is, then, necessary to examine how semiotic mediation takes place and how symbolic resources are used.

Firstly, symbolic resources are used *within the social world*, with respect to the social reality. Symbolic resources can be performative, that is they can be used to indicate one's position into the social context. Symbolic resources can also be semiotic, thus help the individual to explain the current social situation and create meaning upon this social reality. The performative and semiotic functions of uses of symbolic resources are, apparently, interdependent. For example, watching a movie may help the person watching to confer meaning to their current situation.

A second use of symbolic resources concerns *interpersonal relationships*. Similarly, the use of symbolic resources can be performative, meaning to enable the relationship with the other person or persons – either by creating new relationship(s) or maintaining existing. Furthermore, symbolic resources can be, also, used semiotically, thus to facilitate interpersonal understanding. These uses of symbolic resources are interconnected, as well, and may occur simultaneously.

Finally, symbolic resources can be used to transform one's relationship to oneself. These uses of symbolic resources, named *intrapsychic uses*, are related to the satisfaction of various personal needs, like emotional. Intrapsychic uses of symbolic resources aim to maintain a sense of self-continuity while dealing with change throughout transition. Their utility is defined on mediating the relationship with oneself: to reflect upon experiences, to understand inner feelings, to comfort tension or to further explore oneself. The routine of reading the same book before bed for a senior aged person, for example, may function as a reminder of youth innocence.

Consequently, symbolic resources are used about the social world, about other persons and about oneself. These main directions of the 'aboutness' of symbolic resources are dynamically interacting; for example, the use about oneself may emerge through the use about the social world.

Zittoun (2004, 2006) aptly describes the symbolic relation between the person and the element through the scheme of the semiotic prism (Figure 1), a pyramid which represents the semiotic dynamics used by a person. The poles of the pyramid depict the *person* – including all her or his experiences, feelings and thoughts – the symbolic *object*, the *meaning of this object* for the person and the *other* – whether in person or in group – and their meaning of this object. The sides of this pyramid are the processes of semiotic mediation between each pole. In other words, the person interacts with the object, her or his meaning about the object and others' meaning with the ultimate goal of meaning-making. To make this clear, Zittoun explains the use of stories before bedtime by parents: as illustrated by the semiotic prism, the parents (the others) read the story (symbolic resource) to the person (child), creating meaning on this story and eventually adopting a relaxed routine before bedtime. Interestingly enough, the semiotic prism shows that a full semiotic process needs these four necessary conditions in order to happen. Additionally, the interaction with others is determinant as the object can acquire personal significance only if the person's relationship to the object is, to some extent, acknowledged by significant others (Zittoun, 2006).

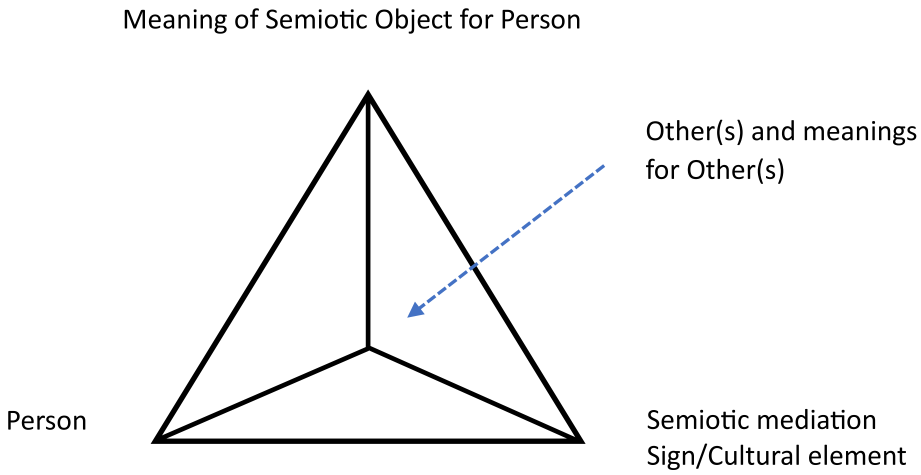

Figure 3.I The semiotic prism by Zittoun (2007).

To fully explore the uses of symbolic resources, I will, also, examine their relation to *time perspective.* Abbey and Valsiner (2005, p.2) argue that “human beings do not merely anticipate what might happen with them, they make something new happen through their actions”, trying to point out how present is influenced by the future. However, present psychological functioning includes the total field of time perspective, thus “psychological past and psychological future” (Lewin, 1942). Accordingly, symbolic resources cannot be explored out of time orientation, since they help people re-establish self-continuity between past and present and move towards the future (Kadianaki, 2010). As Valsiner (2000; p.13) aptly describes, symbolic resources “can re-present ‘facets of already lived-through experience’, co-present something currently being lived, and pre-present possible future experiences”. For all the above reasons, the time perspective dimensions of symbolic resources are interconnected.

There are three temporal dimensions of the use of symbolic resources. Symbolic resources may concern the past, thus may be *retrospective*. Emotional qualities and memory functions are used to bring past elements into the present. This retrospective use of symbolic resources may aim to sooth, to remind, to self-maintain or more.

The use of symbolic resources related to the present is *microgenetic*. This dimension includes symbolic resources used to confer meaning on the here-and-now. Through microgenetic uses of symbolic resources the individual is able to ensure self-continuity (Valsiner, 2003), thus to create a “constant bridging of the immediate past and the immediate future” (Zittoun, 2006). Microgenetic uses of symbolic resources aim to create stability within the microgenetic level of experience, namely the immediate experiences between the “ever-new next time moment in the infinite sequence of irreversible time” (Valsiner, 2007).

Lastly, symbolic resources can be used towards a future perspective, called *prospective*. Prospective uses of symbolic resources may relate to several functions, such as enabling future exploration, consideration of the unknown, encountering possibilities, etc.

Symbolic resources can be used to mediate experiences at various *levels of generality*. Through those different levels of semiotic mediation, the use of symbolic resources may lead to psychological change.

The first level of semiotic mediation is the *immediate embodied perception*. This level can be depicted as the first “contact” with the here-and-now, including all personal reactions to the present experience of the person. Emotions, memories, physical condition or feelings usually appear during this level of semiotic mediation, without clear representation of the feelings experienced. *Local conduct* consists a second level of generality, referring to defining in a more specific way the situation. Experiences are mediated using labelling or categorizing into groups. Situations, experiences and the feelings accompanying them are more definite and lucid now. Then, symbolic resources can be used to enable *categories of the world or of the self*. This level approaches the use of symbolic resources in terms of representing stable categories of self-categories or rules. The individual experiences a balance regarding her feelings, her conduct and her views about herself and the world. The last level of semiotic mediation relates to *commitments and long-standing beliefs* of the person. Experiences are mediated as commitments and principles, which, subsequently, affect the person's feelings, behaviour, perspectives, etc.

It is, therefore, obvious, that different types of uses of symbolic resources are employed to reorganize and reframe the uncertainty experienced in a present situation (Zittoun et al, 2003) with the ultimate objective to cope through transitions and move forward.

3.2.2.2. Using symbolic resources to approach the parents' experience

The rupture of disability

Disability is a rupture that changes the regular flow of parents' life. Following the experience of the diagnosis, the rupture of disability fractures the everyday routines and constrains parents to build an understanding upon that experience, to create meaning. Like parenthood, but also like other individual ruptures, disability is characterised by a level of commitment and permanence. Therefore, the need to create meaning about this rupture may appear to be more imperative.

The characteristics of the rupture of disability are complex but also a rich source of information about parents' experience. Primarily, the rupture of disability may have particular time extension, being at the same time sudden but also slow and recurrent. Whether at birth or not, the diagnosis consists, undoubtedly a sudden rupture; the everyday care that the child with disability needs is, apparently, a slow and recurrent rupture.

As discussed above, ruptures have different origins (Zittoun, 2004; 2006). Concerning the rupture of disability, the causes of rupture are interconnected and not clearly separated. The developmental disability of their children is a rupture which affects any aspect of parents' life. Additionally, having a child with developmental disability is likely to trigger, for example, intra-personal changes, changes in parent's relationships as well as changes in parents' social life.

In terms of relevance, the rupture of developmental disability may appear as an individual rupture. Disability is an individual rupture concerning how each member of the family and, specifically, each parent experiences it, but is still a rupturing event within the family. It could be conceptualized as a family rupture. The same rupturing experience of the child's disability can hold different meaning among parents, which I aim to explore through this research. I am also interested in considering whether there is any positive meaning emerged from the shared rupture of disability, like the rupture of war had, also, positive meaning for the diarist (Zittoun et al, 2008).

Another characteristic that is important, as discussed above, is the degree of generality. The rupture of disability is expected to affect almost all aspects of parent's life and beliefs (specific experiences as choosing a restaurant for the family or beliefs like parent's sense of guilt). Experiencing a rupture of high-level generality means experiencing a wide range of changes for the parent.

As argued above, ruptures generate uncertainty. According to literature, the rupture of disability produces stress (Solnit & Stark, 1961), loss (Partington, 2002) and trauma (Landsman, 1998) but also post-traumatic growth (Joseph & Linley, 2006). This research aims to explore any positive feelings, like pleasure or satisfaction feelings, created by the rupture. This may answer a lot of questions, why for example some parents appear to be especially active in terms of how to manage the new situation of disability or why some of them cope and others don't.

The change of having child with developmental disability is a great rupture regarding parents' understanding and acting. The uncertainty produced by the rupture is followed by the process of transition, towards new forms of stability and balance.

The transition of parenting a child with developmental disability

During transition parents are expected to engage in a process of change. Having experienced the uncertainty of the rupture of disability, parents need to be defined in new ways. As described above, this change includes self-repositioning, developing ways of thinking and learning, and elaborating meaning concerning one's experience (Zittoun, 2004). I consider the life-transition of the child's disability quite particular, including all changing processes of transition. Specifically, I expect that the redefinition of parent's identity apart from the changes regarding the way the parent perceives oneself and is perceived by others and the need to confront new situations may involve questions towards oneself or even guilt. The development of new skills and knowledge in the level of social, practical and theoretical aspects of life will allow parents to deal with unknown fields; for example, parents may need to find ways to cope with the unfamiliar medical or therapeutic terminology or to acquire knowledge on their children's diagnosis and other relevant disciplines. The transition of the child's disability may trigger meaning-making for parents in order to understand the rupture and regain their self-stability: parents need to understand the profound meaning of having a child with developmental disability so as to cope throughout the situation and eventually feel acceptance concerning the experienced rupture.

The transition of parenting a child with developmental disability, apart from skill development and meaning-making, is expected to have emotional and unconscious prolongations as well. Zittoun's research on the transition to parenthood (2004) argues that the relevant transition includes representational construction of the child to come, in the future, and of oneself as the parent of that child. Such representations will influence parent's action and parental role. It is important, though, to note that these representations are based on one's own memories of childhood and relationships with one's own parents, which might evoke several feelings and unconscious conflict issues.

Transitions, as suggested by Zittoun (2006), enable the use of symbolic resources. Accordingly, symbolic resources may help parents of children with developmental disabilities to "work through transition and organise psychological development" (Zittoun, 2006; p. XIII).

Meaning making to cope with the rupture of disability

Parents' uses of symbolic resources are expected to denote the construction of meaning on their children's developmental disabilities and the accommodation of feelings of uncertainty and imbalance produced by the rupture of disability. How symbolic resources mediate the psychological transition of parenting a child with disability? Are there specific symbolic resources used to cope with their children's developmental disability? Music therapy has been found to facilitate skill development and support alternative, non-stigmatised self-perceptions of people with disabilities (MacDonald & Miel, 2002; Magee, 2002). Are there similar or different cultural elements given a personal meaning for parents of children with developmental disabilities? Meaning-making or negotiation of old meanings through the uses of symbolic resources is, anyhow, necessary for the parents in order to move forward. This study is interested to explore these questions.

Cultural elements used by parents as symbolic resources may include a broad range of objects or systems. Religion is expected to be used as a usual symbolic resource, in a supporting or rejecting way. Apart from defining the resources used by parents, I am interested in examining the role these resources have and how they are used in order to cope with the rupture of disability. I also intend to emphasize the connection of resources to their semiotic stream (Lewin, 1942), as, especially concerning parents of children with developmental disabilities, meanings are not isolated from their socio-cultural context. It will also be interesting to underline the “socially stabilized patterns of interaction or customs that encapsulate meanings or experiences for people”, if any (Zittoun et al, 2003).

The uses of symbolic resources may help parents to work through the transition process and the rupture of their children’s disabilities. Specifically, symbolic resources may support parents to understand the rupture of disability, to create meaning upon their children’s developmental disabilities and, ultimately, to achieve coping, namely developmental change (Zittoun, 2006). In general, semiotic mediation – the use of symbolic resources to mediate change – allows the person to do something; this something for parents of children with disabilities may be confronting the stigma, attempting inclusion, claiming their rights, coping with normality, or else. Additionally, as Zittoun points out (2004) the uses of symbolic resources in challenging situation, like the situation of child’s disability, may trigger development of new skills and understandings. This new symbolic creation may mark new ways of parenting after the transition. Therefore, symbolic resources might result not only in what parents intended to do with the cultural elements used (to understand the diagnosis by reading a book, to cope with stigma by going to events) but also in unconscious effects of symbolic resources (skill development, knowledge gaining) (Zittoun, 2004). As mentioned above, the uses of symbolic resources are intended but not always conscious.

The uses of symbolic resources by parents ultimately support their developmental change following the rupture of their children’s disabilities. The question is how parents make use and of which symbolic resources; thus, how they proceed with semiotic mediation and how they use culture to cope with the rupture of disability. This research aims to answer this question.

Conclusion

“We see our minds engaged in making meaning and gaining a feeling of understanding. Such meaning making is essential to living […] Too much consistency hobbles the mind and renders it less able to make meaning”. Josephs & Valsiner (1998) accurately describe how imperative is the need for meaning-making, allowing individuals to comprehend their experiences.

Accordingly, parents experiencing their children's developmental disabilities go through a critical change with special meaning, which they need to mediate semiotically in order to understand it. Child's disability is experienced as a rupture for parents, a disruption in the regular course of life. Parents enter a psychologically demanding state mainly characterised by uncertainty, doubt and incongruity. The need for reorganisation and stability is essential. The process of transition, suggested by the Symbolic Resources Theory, involves changing processes which are expected to facilitate parents' experience. Symbolic resources – cultural elements or systems – are mobilised to confer meaning to their situation but also to help them move forward. Specifically, symbolic resources are employed to support parents in their identity redefinition, skill development and meaning-making. This research is interested to explore these multiple processes, through which parents experience their children' developmental disability.

Chapter 4: Methodology

The aim of this chapter is to present the methodology followed to conduct the study. Firstly, I describe the rationale for choosing qualitative methodology. Then, I explain in detail the different stages of the research process, such as the selection of participants, the methods and process of data collection and the methods of data analysis. Subsequently, I present quality indicators of the study, including issues around public accountability, research validation, reflexivity and transparency. Lastly, I discuss the ethical considerations of this study.

4.1. Qualitative research

The main objective of the qualitative approaches to research is the authentic and holistic description and understanding of a whole, unified social or cultural phenomenon or event (Pourkos & Dafermos, 2010). Qualitative research focuses on the meaning that cannot be studied experimentally, emphasizing on the quality of the phenomenon under study and the particular nature of the experience (Flick et al, 2000). Qualitative methodology, which I selected, aims to describe, analyse, interpret and understand social phenomena, situations and groups in terms of “how” and “why” (Iosifides, 2001). The rationale behind the use of qualitative methodology is explained below.

4.1.1. The rationale behind the use of qualitative method

The purpose of this study was to explore the experience of parents raising children with developmental disabilities, taking into consideration the complexity and quality of this experience. Particularly, this research intended a) to study how parents process the rupture and proceed to transition regarding their children’s developmental disability, b) to explore whether parents engage in any meaning-making process about their children's developmental disability, and if so, what it is and c) to examine parents’ coping strategies to respond to the challenges of their parenting experience. Qualitative methodology was used for this research, as the most suitable to understand and answer the above-mentioned questions.

Firstly, qualitative methodology was considered appropriate to explore how parents create *meaning* about their child's disability. Precisely, qualitative research allows the exploration of processes, structural features and meaning patterns (Flick et al, 2000). According to Willig (2013), qualitative research emphasizes at the meaning and the way people experience events and understand the world, their experiences and themselves, rather than their behaviour. In this research, I gained a deeper understanding of parents' meaning on their child's disability, the process constructing this meaning and its function in several aspects of parent's life. The choice of qualitative methodology intended, exactly, to describe life worlds "from the inside out" (Flick et al, 2000), from the parents' aspect, allowing parents' 'voices' to emerge (Eisner, 1991) and to explore how they understand the determinant experience of their children's disability. Besides, qualitative approach is exploratory in nature (Patton, 2002), descriptive and idiographic – that is, it refers to the description, interpretation and understanding of the topic under study (Isari & Pourkos, 2016) – making it suitable to bring out the meaning of all aspects of the parents' experience of raising their children with developmental disabilities.

Further, this study aimed at gaining a better understanding on parents' *experience as a whole*. The focus of qualitative research is, exactly, on describing and clarifying human experience as it appears in people's lives (Polkinghorne, 2005). Human experience is multidimensional, complicated and dynamic, a "stream of experiences" (James, 1890; p. 229), characteristics which are at the core of qualitative methodology's purpose (Flick et al, 2000). Given that the parenting of children with developmental disabilities is not static over time, qualitative methodology allows for its exploration, emphasizing the different stages of the experience and its changing dimension (Isari & Pourkos, 2016). Besides, the objective of the research was not the investigation of cause-effect relationships or the generalization to the overall population, rather the detailed description, detection and exploration of the quality and complexity of the parents' experience. Qualitative methodology was, thus, chosen because it offers a detail understanding into participants' feelings, behaviour, attitudes and experiences (Tong et al, 2012).

Additionally, my aim was to explore parents' meaning as a *socio-culturally contextualized process*, since disability cannot be approached without taking into account the context in which it takes place. Precisely, the qualitative approach helped to consider the importance of the context and obtain a better understanding of the social, temporal, cultural contexts, around which the participants of the study live their experiences (Isari & Pourkos, 2016). Besides, one of the purposes of qualitative research is to offer insight into the social realities surrounding the phenomena under study, realities which are not known to the broader public but not entirely obvious to the participants themselves (Flick et al, 2000). Consequently, the use of qualitative methodology was related to the exploration of the impact of the socio-cultural context on parents' meaning regarding their children's developmental disability.

Lastly, qualitative research allows the detailed description of *ideas and matters that cannot be studied otherwise* (Isari & Pourkos, 2016). Particularly, this research intended to examine the subjective meaning of parents regarding their children's disabilities, considering the complexity and quality of their experience. It is rather difficult to explore the meaning of the experience using other methods: the objective was not the finding of a statistical average, but the description of the complexity and quality of parents' experience. In qualitative research, this information is derived from the direct contact with the research participants, studying their stories and observing their behaviour, thus approaching their uniqueness (Pourkos & Dafermos, 2010). Flick et al (2000) suggest that qualitative methodology is open and for that reason more involved, allowing to obtain all perspectives of the topic under study. The experience of parenting a child with developmental disability could, therefore, be understood through the description of the uniqueness and the particular texture of their experience, aspects understood by the qualitative methodology.

4.2. Research process

This subchapter is dedicated to the description of the research process. The research process started with the construction of the data corpus. The methods of data collection are, then, presented, namely individual interviews and focus discussion groups. A detailed description of the research process and design follows. The analytical process, finally, concerns the methods and ways of analyzing the data, which provided the results of the research.

4.2.1. Data corpus construction

In this research, participants were selected according to the qualitative-based idea of *corpus construction* (Bauer & Gaskell, 2000). Corpus construction is based upon variables in the form of social characteristics – gender, age, disability, etc. – in order to ensure variety or comparison and not representativeness. Representativeness of the sample is a reliable method to achieve generalized knowledge: the sample represents the population, with the distribution of some criterion being identical in the population and in the sample (Bauer & Aarts, 2000). However, the aim of qualitative research is not a representative sample, but a sample which represents the particular participants, who answer the research question using their skills, knowledge and expertise (Abrams, 2010). The reason behind this is the focus of the researcher in qualitative studies, which is on gaining a deeper understanding of the perspective of the sample of participants (Isari & Pourkos, 2016). Marton (2013) suggests that the term "sampling" is not appropriate for qualitative research, since it is related to the representation and the distribution of certain, already known attributes to the general population (Bauer & Aarts, 2000).

On the contrary, the corpus construction denotes the systematic selection of participants: the corpus is purposefully selected in order to maximize internal variety concerning the topic under examination. Qualitative research examines matters of meaning, phenomena and interactions, which do not concern fixed populations described by known variables. The purposeful construction of data corpus in qualitative research allows to maintain the efficiency of selecting the material to describe the whole (Bauer & Aarts, 2000).

Consequently, the participants of this study were *selected purposefully* and defined in advance, in order to include deviant or extreme cases, typical cases, cases increasing the variety or containing significant cases concerning the phenomenon under study. The above-mentioned idea of corpus construction was considered suitable for this research as the emphasis is on parents' subjective experience, aiming at relativity and not representativeness.

The participants of this research project were selected from the *Early Childhood Intervention Coordinative Service* (ECICS), where I work as a counsellor.

ECICS is a specialized liaison and supportive service of the broader public sector, operating under the supervision of the Committee for the Protection of Persons with Intellectual Disabilities. The Committee as a whole, including the Service, is funded by the Deputy Ministry of Social Welfare. The ECICS Service is dedicated to children of pre-school and school age with intellectual disabilities and/or developmental disorders. The main responsibility of the Service is the coordination of all professionals/services involved, the support and counselling of the child's parents, with the ultimate goal of creating favourable conditions for the child's development. Diagnoses of children whose parents are addressed to the Service mostly concern children with psychomotor impairment, intellectual disability, cerebral palsy, autism spectrum disorder, attention-deficit-hyperactivity disorder, as well as syndromes, like Down, Angelman, Prader-Willi or Williams's syndrome (Committee for the Protection of Persons with Intellectual Disabilities, 2023).

ECICS was considered the most appropriate setting to select the participants of this research. Primarily, ECICS is an independent service, where parents have no emotional involvement, like in other services of the public or private sector (i.e. Mental Health Services, Neurology or Genetic Clinics, Special Education Sector of Ministry of Education, Sport and Youth), where some of them receive their children's diagnosis or assessment. Additionally, the selection of ECICS allowed the required variety of participants that this research programme aimed towards (see chapter 4.2.1.1), since people of various socio-economic (no cost applied for referring to ECICS) and educational statuses, of several nationalities and different family types (such as single parent families, families dealing with complex and multiple problems) are addressed to the ECICS. Further, the Service was considered appropriate and chosen as it allows easy access to parents, since there is no waiting list, no required referral process, offering the option of self-referral.

The role of the counsellor of the Early Childhood Intervention Coordinative Service (ECICS) is to support parents of children with developmental disabilities or parents of children at risk of developing any developmental disability. Support includes consultation about the diagnosis, management of the feelings related to diagnosis, approaching issues regarding acceptance or not of disability, understanding of the presenting condition, management of child-related issues in various contexts and any other psychosocial and emotional support. Support is offered in person, in couple or in parents' groups. Help with any practical issue related to the child's disability is also offered, including promotion of the rights of children with developmental disabilities, research on the diagnosis, gathering information about institutions and services dealing with disability and arrangement and involvement in multidisciplinary meetings. The double role as a counsellor but also as a researcher might raise some challenges, which are discussed in chapter 4.3.2.

4.2.1.1. Criteria for participants' selection

The sample used in this research consisted of parents of children with developmental disabilities. Sample included parents of children diagnosed with intellectual disability, global developmental delay, autism spectrum disorder, cerebral palsy, epilepsy, Down syndrome and Cornelia de Lange syndrome, according to the diagnostic manual DSM-V

(American Psychiatric Association, 2013). The reason of the selection of parents of children with several diagnoses was related to the aim to maximize variety and gain a deep understanding of different parents' experiences, with no intention to generalize the findings of this study (Flick, 2009).

Another criterion was children's age, selecting parents of preschool and school-age children, aged 4 to 12 years old. This selection allowed an appropriate time distance since the transition experienced by parents when their children are firstly going to school, usually at age of 3-4 years old, the disengagement from the child and the probable emotional reactions may not allow parents to pay attention to their experience with their children with disability. Another reason is the usual discharge of parents from their children's continuous care after entering school, allowing more time without their children, time for thought and contemplation. The upper age limit of 12 years was set as a common transition point to another school level, high school, where other priorities for parents and children begin: therapeutic interventions may decrease, introduction into adolescence and the importance of peer interaction are the focus of children and parents.

Another inclusion criterion was the minimum two-year period since parents received their children's final diagnosis. This was supposed to be a considerable time space, which allowed parents to have been relatively adapted to the new data of disability, to reflect on the meaning of disability, as the initial and related-to-diagnosis emotions are expected to have been – at least partly – relented. The aim was to emphasize on parents' feelings and understanding of their children's condition rather than feelings associated with the distress of the diagnosis exploration, the diagnosis itself and its severity.

In order to explore as many aspects of parents' experiences as possible both mothers and fathers of children with developmental disabilities were asked to participate in this research project. In most previous relevant researches, mothers are overrepresented or often the sole participants (Graungaard, 2007). Besides, research confirms that mothers hold different perceptions on their children's disabilities (Leigh, 2007) than fathers and present different ways of coping with the uncertainty of disability (Graungaard, 2007). Differences on each parent's roles – mother as the basic caregiver in families without but also in families with a child with disability – is also indicative of social conditions and especially the deeply gendered nature of social and cultural processes. An important goal of this research was to point out those differences and gain a deeper understanding on the subjective meaning and personal experience of each parent. The selection of participants ensured the representation of various educational and socioeconomic backgrounds, allowing the consideration of different perspectives and the diversity of data (Gaskell, 2000). Lastly, parents who do not speak fluent Greek were excluded, to guarantee eloquence of expression.

4.2.1.2. Constraints in corpus construction

According to Cornish (2004), every part of a research project, but particularly selection of participants, consists a process full of potential and restrictions. The corpus construction of this research was based on the above-mentioned criteria. However, some constraints were identified.

A necessary requirement for research participation was the participants' willingness to contribute, namely their decision to spend time – focus discussion groups were especially time-consuming – and share sensitive information about their lives. As expected, some parents were not interested in participating in the research.

Another constraint of the corpus construction was the overrepresentation of mothers, as suggested in previous researches (Graungaard, 2007). In spite of approaching several fathers in order to participate in the interviews, individual or focus discussion groups, the final number of the participant fathers was limited compared to the participant mothers. Of course, since the objective of qualitative research is not representativeness, there was no reason to have strictly equal number of mothers and fathers participants. Besides, the larger participation of mothers in this research project seemed to be related to their parental and caring role, which is further analyzed in chapter 7.

Another important factor, essential for conducting this research, was the familiarity with the participating parents. The significance of familiarity concerned both parties, that is both the parents and me as the researcher. With most of the parents there was a familiarity and trust relationship, having already met with them several times within the framework of the ECICS Service and already knowing many details about their lives and their children. However, there were 4 parents whom I met for the first time during their interview. These parents participated in the interviews following the suggestion of their husbands and wives, who also participated in the individual interviews. Despite lacking intimacy with these parents, there was a kind of familiarity since I already knew details about their children, through their husbands or wives. Additionally, approaching and understanding the experience of two parents raising the same child was considered a particularly rich source of data.

4.2.1.3. The final data corpus

The corpus of participants was constructed, using information of the ECICS records, based on the criteria mentioned above. The initial list included more parents than I was aiming to recruit (52 parents), as not all of them were expected to accept the invitation for the research. My role as a counsellor seemed to help parents feel safe for participating in this research project due to the trust relationship we had previously developed, including discussing in detail about their life with their child with disability. First contact with participants was by telephone, where the purpose of the research was explained, their contribution, their right to express complaints and to leave the research project at any point they wished. Emphasis was given to the fact that the project strictly followed the principles of respect and confidentiality. Participants had time to consider their decision. The children's diagnosis was confirmed through parents' reference during the interviews, with no medical certificates or other personal data required from parents.

The *final corpus of participants* in this research project consisted of 26 parents of children with developmental disabilities, 18 mothers and 8 fathers aged between 33 and 58 years old. Twenty-four of them contributed with an individual interview and six participated in the focus discussion groups, with four of them participating in both. Among the participants, there were five couples of parents who were both separately interviewed. There were 24 individual interviews and five focus discussion groups conducted. More details about participant parents' demographic characteristics are described in appendix I.

The number of participants was based on the theoretical and practical aspects of qualitative research. As mentioned above, case contrast and variety were the main criteria in corpus construction rather than sample size (Kelle, 1997), as the objective of qualitative research is to identify patterns of multiple comparisons between deliberately chosen individual cases (Flick et al, 2000). Case contrast refers to the feature of presenting multiple patterns of data within the selected sample (Flick et al, 2000). Corpus variety indicates the level of variation of data where no new categories of data can be identified (Willig, 2013).

The basic idea guiding qualitative research sampling is theoretical saturation: when no new information is obtained from new participants (Kvale, 1996). Saturation stands at the point where research has become "counter-productive" and "the new" discovered does not necessarily add anything to the overall project (Strauss & Corbin, 1998). However, the research community has not achieved proper systematization of the principles and application of saturation (Morse, 1995). To control this limitation, the criteria of basic content saturation will be applied, thus the repetition of main themes (Gillespie, 2004) within the limits of the particular social arena and the research time frame (Kadianaki, 2010).

Consequently, the number of 26 participants was considered a large enough corpus to reflect the variation within the target population. Considering additionally all relevant practical issues, as the time-consuming process of transcription and coding, this number allowed the collection of satisfactory bunch of data, whereas further interviews were expected just to confirm already acquired knowledge (Lindlof, 1995).

4.2.2. Data collection methods

4.2.2.1. Individual interviews

In-depth semi-structured interviews were considered a suitable method to collect data and approach the questions of this research project.

Interviews enable the emergence of the participant's view on their world through their own speech, offering a rich, in-depth understanding of the participants' experiences and their subjective meanings attached to these experiences (May, 2001). Interviews also extend the researcher's picture on the participants' view, allowing a deeper insight of various aspects of their world, which cannot be approached otherwise, such as feelings, thoughts, intentions or the participants' reflection about their past and their future (Patton, 2002). Gaskell (2000) argues that interviewing is the entry point to map and understand the participants' life. Thus, interviewing concerns the narrative of the participant's experience, that is affected but also affects the way in which the individual interprets things.

However, the aim of the research was not only parents' thoughts and opinions, but also the meaning of this experience for parents. The interview allows an interpretation of the interviewee's meaning on their lives and relationships, since it covers both a factual and a meaning level (Kvale, 1996), which are central for this research. The meaning of their child's disability was also constructed from parents' narrative, the speech they chose to use and the overall, verbal and non-verbal communication during the interview. Furthermore, interviews are recommended for particular sensitive issues, such as parents of children with disabilities discussing their experience (Bauer & Gaskell, 2000).

Concerning the interview procedure, participants had agreed to their voluntary participation in the research through the first telephone contact I had with them. At the beginning of each interview, I briefly introduced again the topic of the research, explaining that I am a research PhD student interested in understanding the experience of parents of children with developmental difficulties[11]. After being appropriately informed, participants gave their written consent to participate (see consent form for interviews / focus group, appendix B), I also informed the participants that they can share with me as much information as they feel comfortable doing so and if they do not wish to answer a question, that will be completely respected. I, then, explained, the need for using a recorder, specifying that they could ask me to pause or turn it off if they wanted to during the interview.

Most interviews took place in the participants' houses, in order to ensure a quiet place but also feeling comfortable and safe in their personal space. For practical reasons, conducting the interviews at the parents' house was not always possible (i.e. in the presence of other family members). In that cases, other places were used, such as teaching rooms at the University of Cyprus, the head offices of ECICS or the parents' working place, always prioritizing the interviews' privacy and participants' convenience. Additionally, five interviews were conducted virtually, through online zoom meetings, following the existing Covid-19 measures of the time. It is important to note that the period of the interviews was the initial period of the outbreak of the Covid-19 pandemic and some participants were quite hesitant in their participating in the interviews. Some parents were more restricted than others due to their children's physical vulnerability, because of their diagnosis.

At the beginning of each interview, some time was given for both the interviewee and myself as the researcher to feel comfortable, spending some minutes for small talk and general questions about their children (how are they doing, what class they are in, etc). The collection of participants' demographic information followed, including age, profession, education, marital status, country of origin and support network. I used an interview guide (see appendix D) to set out the key issues I wanted to explore, while allowing the discussion and following the participants' narrative. During interviews, several participants asked for clarifications on some questions asked, for example if they consider that they have accepted their child's diagnosis.

The duration of the interviews ranged between 60 and 150 minutes. All 24 interviews were conducted during a period of 11 months. During the interviews, I used standard Greek language, whereas most of participants used Cypriot dialect. Particularly, 16 participants

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[11] I purposefully avoided to mention terms such as disability, autism, syndrome, spectrum, disorder, delay or else, as I wanted to explore the parents' own meaning – without imposing any given representation – about their children's disability but also their understanding about these terms. In case such terms were mentioned by the participants, I followed their "terminology".

used Cypriot dialect, 5 participants used standard Greek and 3 participants used Greek or Cypriot fluently enough but that was not their native language. All participants were recommended to use their native language – since I am very familiar with Cypriot dialect and standard Greek is my native language – with no need to adjust their way of talking. Most of them, though, because of our previous contact through ECICS, didn't need this clarification, as they already knew that and spoke their native language. At some points of the interviews, where I was not sure if I understood exactly what the participant was saying, I asked for clarifications. During interviews, I took short notes, writing down key words that participants mentioned. After each interview, I took extensive notes, regarding several points of the interview or the feelings left at me.

At the end of each interview, participants reported that they felt comfortable during the interview. Each interview was for me like a small revelation, because even though I already knew their families and almost all of the participants, I felt that they shared with me parts of their lives unknown to me until then, allowing me to enter very sensitive fields for them and to discuss issues that they themselves probably did not usually reflect upon. During interviews, parents shared generously their emotions, such as sadness, anger, despair but also motivation and optimism. Many participants were sometimes quite emotionally charged, as the topics discussed brought back key events in their lives, such as their child's diagnosis or feeling alone throughout the child's diagnosis. Humor was, also, evident in the narratives of the majority of parents, either in their descriptions of past events or in their interpretation of certain incidents. For me, as an interviewer and a listener, most interviews were riveting and highly interesting, illuminating parts of the parents' lives that I never thought of. Further, most of the interviews left me with various issues to reflect upon regarding parenting, developmental disabilities and the ways they are handled in the Cypriot context.

4.2.2.2. Focus group discussions

Focus group discussions were, also, used as a data collection method. Focus groups allow the expression of participants' views on a specific topic within a group where the participants have one or more common attributes (Kitzinger, 1994). Some researchers describe focus groups as a kind of interview, where participants have the opportunity to hear other participants' views and react on those views (Romm, 2015). The researcher becomes the moderator, trying to emerge participants' experiences, their perceptions and their representations on the research topic. Those elements stem from the interaction between participants (Macnaghten & Myers, 2004), which is the distinctive feature of focus groups where data come from (Kitzinger, 1994). Gaskell (2000) describes focus groups as a genuine social interaction, as “the minimal social unit in operation, and as such the meanings or representations that emerge are more influenced by the social nature of the group interaction” (Gaskell, 2000; p. 46). Lastly, focus groups represent a public discussion situation, a collective process that prevents the isolation of the individual (Flick et al, 2000).

Happening in a more natural and unstructured context, compared to individual interviews, the focus discussion groups allowed a more unprompted approach of parents’ social representations and their shared meanings (Bauer & Gaskel, 2000). Additionally, the focus groups gave participants the opportunity to interact with other parents in a similar position, to consider different opinions and to exchange beliefs on a common experience they have to handle on a daily basis. Different life stories but also similar processes came onto the surface and contributed to a better understanding of what does a child’s developmental disability mean for their parents. Additionally, focus groups seemed to help participants reflect on different approaches concerning their children’s disability, offering them an opportunity for self-growth through the focus groups.

Regarding the sequence, I chose the group meetings to follow the individual interviews for those participating in both, in order to ensure that group discussion would not influence individual expression during the interviews. Focus groups consist dynamic processes, which may impact on participants’ perspectives (i.e. change of opinion) or “complex collaborative projects” (Myers, 1998; p. 85) which enable the interaction, while forming, changing, stating, or exchanging views and attitudes in everyday social life (Flick et al, 2000). Thus, this sequence allowed exploring the pure individual insight of parents’ meaning and then the interaction within the group. Additionally, having identified significant issues during interview, I was able as the researcher to see how participants handle these issues within the group dynamic. However, this sequence was not always possible to strictly observe, due to parents’ limited availability. Thus, one of the interviews was conducted after the focus group.

Concerning the focus group procedure, I conducted 5 focus discussions of 6 participants, which lasted approximately 90 minutes each. Organizing of the focus discussion groups proved to be more complicated and required special management. Participants were informed about the groups after the end of each interview, asking to indicate their availability and interest in participating. However, there was no adequate response, very few were interested and their availability did not lead to a commonly agreed time. All parents mentioned the difficulty of finding the extra time to participate, due to the demands of caring for their child (therapies, education, therapeutic homework, socialization or other), something they often mentioned in the interviews as well (see chapter 6.1 and 6.2). After a few months, I contacted again some of the interviewed participants, informing them that I will conduct some parents' group meetings as part of my research and as a continuation of their individual interviews, asking them to participate. The group was described as a parent group with a research interest. The purpose of this format aimed to give parents the motivation of personal development and support in order to join the group. Most parents were excited about the creation of such a group. Quite soon, I had 4 positive answers from parents interested to participate in the group. At the same time, 2 parents not participating in the individual interviews were informed by the others and contacted me themselves to join the group, which I accepted.

The time, date and place of the focus group discussions was set by me and all six parents agreed to participate. The group included 8 successive weekly meetings at a specific time and day. The first 3 meetings were dedicated to developing a trusting and safe environment for participants and allowing them to feel familiar with each other. During the 2nd group meeting, I introduced the purpose of the research and I explained the necessity of using a recorder, clarifying the confidentiality of the data collected, with the same way as in individual interviews. Some participants asked for time to consider their response. During the 3rd group discussion, all participants gave their oral consent both about the research and the use of the recorder, which I started using from the 4th group discussion until the last one. Parents were very consistent in their participation to the meetings, with only 2 parents being absent once. Three out of the six parents were working at the time of the meetings and needed to take special leave from their employers, which they did.

The place that the focus discussions took place was a big lecture room in the Multifunctional Center of Nicosia Municipality, a quiet place that ensured privacy. I set up the room accordingly, with the chairs in circle, so as all members of the group could look at each other. I used a discussion guide (appendix E) to make sure that some key issues would be discussed, such as reception of diagnosis, representation of disability or meaning of child's developmental disability. However, I tried to let the discussion open and follow its flow, minimizing my involvement. My role was strictly that of the moderator, remaining discreet, allowing the development of parents' dialogue and making sure that all participants was having enough time to speak. Some parents were more talkative than others, where I tried to subtly involve those who were quieter. I took short notes during the group discussions and more extensive ones after each meeting, just like in the individual interviews.

Again, the focus discussion group meetings brought out many emotions, such as sorrow, anger, anxiety, loneliness but also hope. During the group discussions, I felt the parents' obvious need to talk about what they were experiencing. Even though the parents did not know each other beforehand, the familiarity of the group was evident, arising from the shared experiences and feelings, which allowed in-depth discussion. Among the exchange and sharing of parents' insights, there were disagreements but also moments of laughter and excitement, confirming the dynamic of the group as a living form of interaction. For me, as a moderator of the focus group discussions, I felt captivated by the narratives but also by the interaction between the parents, which proved to be valuable material for the research process.

4.2.3. Pre-analytic procedure

4.2.3.1. Transcription

I transcribed myself all data collected from individual interviews and focus discussion groups. I used a digital foot pedal device during all transcription procedure. To limit the loss of non-verbal elements, I included references such as pauses, emotions, frustration, laughter, smiles, nodding, etc. I took short notes along with the transcription of each interview – individual and group – writing down comments on the participants' narratives.

The process of transcription was very time-consuming (i.e. approximately 10 minutes to transcribe 1 minute of recorded interview). However, the transcription of each interview or group discussion allowed me to re-experience their process and to identify new elements that I had not noticed before and resulted in acquiring a particular familiarity with the whole corpus of data.

4.2.3.2. Coding

Coding is the process where data are separated in smaller sections, categorized and basic meaning units are identified out of them (Flick, 2009). According to Flick et al (2000), coding is the naming of concepts identified in a text, which the researcher explains and discusses in detail. However, the code emerges from the text and is not imposed by the researcher (Mantzoukas, 2007). When all data have been coded, the coding list is produced, including all names of each concept of the list and a short explanation of each code.

I coded all data, line by line, trying to recognize meaningful concepts and categories. I used Atlas.ti software program, in order to organize my data and the produced coding lists. I identified a preliminary list of 71 codes, which I reviewed extensively and narrowed down to 48, then to 42 and then to a final list of 39 codes (appendix G), common for both the individual interviews and the focus discussions. This procedure was largely assisted by my academic supervisor, who also reviewed the list of codes several times and directed me with her valuable remarks to further develop it. I also reviewed the preliminary list of codes with a fellow PhD researcher of the Department of Psychology.

The next step was to place the 39 codes into broader clusters of codes, namely groups of codes which I found had a degree of relativity. For example, the cluster "the path towards the diagnosis" included the codes "the process of the diagnosis", "the announcement of the diagnosis and the parents' reactions" and "the communication of the diagnosis towards others". Overall, I created 9 clusters of codes (appendix H). At the end, I edited the codes' names, adding as well a short text explaining what each code represents and what each cluster describes.

4.2.4. Data analysis methods

4.2.4.1. Thematic analysis

Concerning the method of analysis, thematic analysis was used in order to analyse the data collected. Thematic analysis is described as a search for themes that emerge as being important to the description of the phenomenon under study, a form of pattern recognition within the data (Fereday & Muir-Cochrane, 2006). Themes are significant and prominent meaning units of the data about the research questions, representing some motif of meaning within the data set. The "keyness" of a theme is not necessarily dependent on the majority of reports but on the significance of meaning and/or on the contradictions within data (Braun & Clarke, 2006).

Thematically analysed data represent significant concepts and reflect researcher's interpretation on participants' perspectives (Willig, 2013). Thematic analysis was, thus, selected as appropriate to describe the way people understand and think upon certain issues and suitable to depict personal experience, as the experience of having a child with developmental disability.

4.2.4.2. The step-by-step procedure of thematic analysis

As an orientation tool throughout analysis, I used Braun & Clarke's (2006) thematic analysis steps. Firstly, I familiarized myself with the data. Transcription, as mentioned above, helped me a lot through this process, listening to the interviews and the focus discussions again and again to the point where I learned parts of them by heart. However, at this point it was significant that I was taking notes with patterns of meaning or other initial ideas. Coding followed, as described above, organizing systematically all data. Through coding, I aimed to deconstruct data to the "most basic segment, or element, of the raw data or information that can be assessed in a meaningful way" (Boyatzis, 1998; p. 63), producing a list of codes. During the coding step, I tried to code the data inclusively, keeping the surrounding data and context of each extract. Additionally, there were extracts which I coded more than once or extracts that remained uncoded.

The next step was the exploration for potential themes. I initially reviewed cluster of codes which I considered closer to my research questions and left behind other clusters which I considered not highly related, for example cluster 2 (how others approach disability issues and how others approach parents of children with disabilities). This step included reading each code's report separately and taking extended notes with comments about possible concepts identified. At the same time, I tried to recognise if several codes could be combined to form a main theme. To do so, I highlighted comments using different colours, trying to indicate and remember codes which are close to one another and could form a theme. The ultimate purpose here was to organize relevant codes into potential themes, in a way that they would allow me to identify a meaningful story behind the data (Willig, 2013).

Analytical review of the potential themes was the next step. This was about a profound refinement process, where initially I checked if the coded extracts of each theme really represent the particular theme. At this point, I recognized extracts within specific themes which didn't fit – which I moved to other more relevant – but also extracts within multiple themes which would produce a new theme. I also refined the entire data set, checking if there are any relations between the themes and if I could integrate some of them. During this step, I realized I had some themes which formed a broader thematic section, which I decided to keep as such. For example, the thematic section "how the parent experiences the child's developmental disability" consisted of several themes, namely as a burden, as a blessing, as a struggle or as a "no-different" parenting experience. This step involved a lot of back-and-forth reviewing, where I returned several times to the raw data and checked if they are essentially represented within the thematic list, revising the list if needed.

The next step was the exact definition of the final themes. While naming and describing the themes, I tried to use comprehensive definitions, which represent the “essence” of what each theme is about (Braun & Clarke, 2006; p. 22). I had to rename some themes several times until I reached a satisfactory definition. I wrote down the final extended thematic list, including definition, description of each theme and data extracts which reflect each theme.

The final step of the thematic analysis was the production of the report of analysis. Initially, I created a short version of the thematic list, to help myself consider the themes as a one-piece text. I, then, reviewed again the final thematic list, trying at the same time to interpret them. I used the questions suggested by Braun & Clarke (2006) in order to assist this interpretive work: what does this theme mean? Why the participants discuss this theme in this particular way? During this last analytical step, I took extensive notes, with key words, shapes, figures, groupings and other spontaneous ideas that helped me develop my thinking and interpret the data. The final analysis of the data produced 3 major topics of analytical discussion: I. the milestones of the parenting experience, concerning the parents’ experience of the diagnosis, the parents’ interpretation of the diagnosis and the social implications, I. the parents’ personal experience, analyzing the meaning, the feelings and the resources of parenting children with disabilities and III. the parents’ identity, concerning parents’ self-identity, parents’ loss of self and parents’ social self.

4.3. Transparency and quality of the study

Qualitative research is based on the idea of no-objective reality, as knowledge is produced by processes which are context specific (Willig, 2013). In that case, which are the criteria of assessing the quality of the qualitative research? Ensuring the quality of research findings in qualitative research is a large discussion among researchers, with no specific answer. The criteria used to assess the quality of quantitative research – namely validity, reliability and generalisability – do not apply and are not suitable to assess the quality of qualitative research (Korstjens & Moser, 2018).

Literature suggests several processes to achieve transparency and quality in qualitative research. Bauer & Gaskell (2000) recommend the criteria of confidence and relevance, meaning that the public accountability of a study concerns the degree of confidence towards the researcher and the relevance or utility of the findings within external reality. Flick (2009) introduces the term “procedural validity, which represents reflexivity of the research and clarity of the research processes. Clarity, transparency and coherence throughout the research process is another common answer to the required criterion of the quality of qualitative research (Foster, 2001).

In this qualitative study, to ensure the quality of the research I focused on the triangulation of the findings, on my reflexivity as the researcher, on transparency and on the thick description of the results.

4.3.1. Triangulation

Triangulation is a kind of verification, using complementary theories, methods, data or investigators, in order to achieve a deeper and broader understanding of the research questions (Flick et al, 2000). The purpose of triangulation is to improve the process of the qualitative research (Sim & Sharp, 1998), limiting the problems of the individual researcher (Flick et al, 2000), namely the one-sided perspective, and decreasing the possible limitations and biases of a single method.

In this research project, I used method and investigator triangulation, in order to expand my understanding on the topic and to ensure the quality of this study.

Method triangulation is the use of multiple data collection methods in order to study a single phenomenon (Polit & Beck, 2012). Method triangulation was followed in this study, using two data collection methods: individual interviews and focused discussions. This is considered a within-method triangulation, as both methods apply to qualitative research (Denzin, 2009). The individual on the one side and the group dynamic on the other, allowed me to gain a deeper understanding regarding parents' experiences and meaning on their children's developmental disability.

Investigator triangulation is the involvement of different researchers in order to study a single phenomenon. This kind of triangulation aims to limit the biases during the several research processes, such as coding or analyzing the data (Boyd, 2000). The outcome of the investigator triangulation can be the confirmation of the findings but also the development of different perspectives (Denzin, 1978).

Investigator triangulation was applied in terms of coding. Particularly, I used the Intercoder Reliability (ICR) suggested by O'Connor & Joffe (2020), which is a measure of the agreement between the investigators. Specifically, I randomly selected one individual interview and one focus discussion and asked from another coder, a fellow PhD researcher of the Department of Psychology, to code the data. The coder used Atlas.ti, as I did, when coding the data. Intercoder reliability was assessed using the actual coded data, the percentage of agreed, not agreed data and grey areas, which indicated a moderate agreement between coders (68%). This was due to lack of clarity of the definition of some of the codes. After proceeding to the necessary clarifications, I repeated the process, asking from a third coder, another fellow PhD researcher of the Department of Psychology, to code the same individual interview and focus discussion, indicating a satisfactory level of agreement (86,2%). During this process, I discussed extensively the coding list with the two complementary coders, where we had the opportunity to identify areas of disagreement.

Investigator triangulation was applied in terms of analysis, as well. My academic supervisor, Dr Kadianaki, and myself, had access to the analysis of the data, by reviewing the process of interpretation of data (Banik, 1993). This kind of triangulation helped my way throughout analysis, by developing my analytical perspective and enhancing the produced report of the analysis.

4.3.2. Researcher's reflexivity

The researcher in qualitative research remains active throughout the research, being the same person observing, describing and interpreting the phenomenon under study. In other words, the researcher's identity cannot be removed to "clear" the data (Howarth, 2002), whose identity both influences and is influenced by the research conducted by the researcher (Ponterotto & Grieger, 1999).

4.3.2.1. The researcher as insider and as outsider

As the researcher, I was holding several roles, corresponding to different aspects of my identity, in relation to the participants: some aspects of my identity were placing me as an outsider and some as an insider in the field of research.

Gender and age, as the main features of my identity, being a 41-year-old female, seemed to have positively impacted on the research process, as I had a similar age with a lot of participants, with most of them being women (19 out of 27 participants). Another interesting aspect of my identity is my parental role, which definitely influenced the way I approached the research questions but also seemed to raise parents' expectations for my understanding. Actually, at the beginning of this research project I was not holding this identity, as I became parent before the beginning of the data collection. This transition seemed to have expanded my perspective, challenging my previous beliefs about parenting and about my philosophy of life in general.

Other aspects of my identity, were placing me as an outsider regarding the group of participants. My nationality, as a Greek immigrant in Cyprus, possibly gave me a role of an outsider for many Cypriot participants. Besides, non-Cypriots participants perhaps considered me as an insider, sharing a common characteristic with them, as immigrant parents living in Cyprus. Another significant for this research project feature of my identity is that I have no experience of disability in my close environment, which could probably enable thoughts of reaction, defence or anger ("you don't understand") or increased efforts to explain from the part of the parents. Being quite familiar though with disability issues, which parents are aware of, and holding already a good professional relationship with most parents, where they had the chance to explain their difficulties at the first place, I did not notice any relevant impact on how I was represented by the participants.

All the above-mentioned traits as insider or outsider are considered to have influence the research process through the researcher-participant interaction, while having some substantial impact on how I, as the researcher was interpreted and understood by parents (Cassell, 2005).

4.3.2.2. Researcher's familiarity with participants

An attribute that seemed to compensate enough for being an outsider was the fact that I was very familiar with the research participants. I am working as a counsellor of the Early Childhood Intervention Coordinative Service (ECICS) for 14 years, interacting and having established a profound and trustworthy relationship with parents of children with developmental disabilities, deeply acknowledging their difficulties and problems in the local context. Additionally, I had a very good relationship with most of the participants parents, which impacted positively the research atmosphere relation. It is important to mention that several parents welcomed me in their houses, for the research purposes.

4.3.2.3. The double role of researcher and counsellor

Another point that I reflected upon is my double relationship with the participants, as a researcher and as a counsellor of ECICS, which might bring to the fore other parts of my identity as a professional. Working at the Early Childhood Intervention Coordinative Service (ECICS) gives me the role of the support person, in direct contact with parents of children with developmental disabilities and familiar with disability issues. Additionally, as a counsellor, I represent a reference person, non-negatively charged and actively hearing parents' problems. My double role as the counsellor and the researcher at the same time might raise some challenges during the research process. Initially, there is a change in my role – from a counsellor becoming a researcher – which results in the change of parents' role – from a counsellor client becoming a participant. Most parents, though, seemed to be able to manage this change. However, my different role from the usual one as counsellor for parents, thus my role as the researcher, positioned me in a role of a person asking to know, instead of providing support. My role as the researcher, asking to know, made the relationship with parents more equal, providing me with a lot of information and helping me to achieve a deeper understanding of the research topic.

The main challenge of this double role, though, is the conflict between offering counselling and conducting research; this way, the necessary distance between me, as the researcher and the participant is reduced. Further, my role as the counsellor might contribute to me being emotionally involved with parents and more biased (being aware of their struggles, their concerns and their efforts), with them as participants. However, the objective in qualitative research is not to provide some objective knowledge but to shed light to the participants' perspective, which will be supported by the research data (Flick et al, 2000). Besides, counselling is another professional area determined by strong ethical principles, with the relationship with parents being professional and not personal. It is important to note, finally, that ECICS responsibilities do not include clinical work (ex. management of psychopathology) but counselling towards parents in issues related with their children's disability and other every day issues. Consequently, my double role could raise some challenges which did not, however, result, in conflict of any way for the research process. This double role of the researcher and the counsellor at the same time seemed to have some positive aspects, instead. An advantage was that parents were already familiar with me as the researcher and felt more comfortable to share personal information. Another positive aspect of this double role was the increase of the researcher's motive. Offering counselling towards parents and often focusing on their issues of acceptance, increased my motivation as the researcher to explore parents' experiences.

Self but also peer reflection and self-development helped me a lot to assess the outcome of this double role. Academic supervision for my role as the researcher but also clinical supervision, for my role as the counsellor, which both started in advance (before contacting participants or collecting data), were considered adequate methods for the management of this double role.

4.3.2.4. Examining the researcher’s beliefs and biases

After a long time of working with parents of children with developmental disabilities, I have, unavoidably, formed my own biases and beliefs towards them. Trying to be aware and continuously examine these beliefs and biases was a necessary practice during the research process.

For example, I used to hold the general idea that parents tend to declare acceptance, even though it was obvious to me that they hadn’t recognized their child’s diagnosis. Through this research, parents’ narratives made me realize that acceptance is not one-dimensional, is related to several perspectives of the parents’ experience and is not the only issue parents are dealing with. Besides, reflecting upon this belief of mine, I questioned why parents declare acceptance and if their attitude is influenced or determined and to what extent by the social context they live in.

Additionally, parents’ detailed sharing of their everyday life, through their participation in the study, challenged my previous understanding on how they live. I had the representation of parents of children with disability living an unhappy and disappointing life, which does not represent at all most parents. For example, parents described a life full of frustration but also motivation, moments of happiness and moments of sadness, a life of tears but also a life with contentment. This balance was obvious, even when the parent interviewed described a rather difficult to live with disorder or disability. Lastly, most interviews and general interaction with parents during the whole research process was rather pleasant and didn’t leave me any sad feelings.

4.3.3. Transparency of the study

Bauer & Gaskell (2000) claim that the critical components of the quality of research is transparency, good documentation and clarity of the research process. Particularly, they discuss several ways of ensuring transparency in qualitative research, which is the thorough description of the participants’ selection, of the interview or focus groups guides used, of the coding frame of the analysis, of the method of data collection and of the method of interviewing.

In this research project, transparency and clarity were ensured in several ways. As a principle, I described adequately every step of the research process, such as the corpus construction, the data collection methods, the pre-analytic procedure and the data analysis methods used. Regarding the data corpus construction, I outlined every detail concerning the criteria of selecting the participants, the limitations I faced and the final data corpus, explaining every relevant decision I took. As to the data collection methods, I discussed and provided the topic guides of individual interviews and focus groups discussions, open to be reviewed. Concerning the pre-analytic procedure, apart from explaining the process of coding, I provided the final list of codes. Finally, the data analysis methods were described in detail, including the 6-step procedure of the thematic analysis and how the coding frame presented above concluded to the particular analysis of the data.

Overall, by presenting comprehensively and in every detail all the research processes and my choices regarding the research design, the methods used and my way towards the findings and the conclusion of this study, I enhance the transparency and, consequently, I ensured the quality of this research project.

4.4. Ethical implications

Research ethics is particularly significant in qualitative research, since this kind of research provides a deep understanding of aspects of human experience not easily accessible and deals with sensitive data regarding the participants' dignity, self-determination and interests as a person (Flick et al, 2000).

The first step of ensuring the ethical aspects of this research project was to apply to the Cyprus National Bioethics Committee and receive the relative approval in January 2020 (appendix A). Written permit was also provided by the *Early Childhood Intervention Coordinative Service* (ECICS), where the participants were recruited from.

4.4.1. Confidentiality and anonymity

This research followed the rules of confidentiality and anonymity of participants. In terms of confidentiality, participants were appropriately informed prior to data collection, provided their informed written consent. Participants' personal information was handled with respect, following the principle of confidentiality. According to the Act about Personal Data Processing (Official Gazette of the Republic of Cyprus, 2001, article 5), personal data should be used only when participants have provided their consent. Participants, after being thoroughly informed by me, as the researcher, about the purpose of the research, their rights and the use of tape recorder for data collection purposes, were asked to provide their written consent.

In terms of the research content, a potential ethical concern raised was whether any participant would feel distressed during the interviews or the focus group. For that reason, I prepared in advance a list of counselling or support services, where parents could be self-referred to (free of cost), which was provided to all the participants (see page 4-5 of consent form and appendix C). However, parents didn't report experiencing any intense feelings or feeling distressed during the interviews or the focus groups, when asked.

In terms of data security, collected data was archived anonymously and kept confidential. The data from the individual interviews and the focus discussions was collected by me as the researcher. The audio recordings were transcribed on written form by me, the only person involved in the data collection and transcription. Anonymisation protocol was applied, using pseydonyms to all participants and ensuring removal of any identifying information (place of residence, occupation, etc). Other data provided, such as names of all their children, their spouses, members of the broaden family (grandparents, uncles, etc), professionals (doctors, teachers, therapists, etc), everybody mentioned by the participants (i.e. their friends mentioned in their narratives) and some of the names of the children's diagnosis (names of rare syndromes) were replaced by pseudonyms. The only true names were mine, as the researcher, and the name of my academic supervisor. Other data that was not concealed was the information included in the public discourse, such as names of books, films, authors, etc. No-one else, except from me, as the researcher, had access to the original data or the list matching the pseudonyms with the participants' real names and details. My academic supervisor, Dr Irini Kadianaki, had access only to the anonymized data. Any extracts used for purposes of publication, including PhD thesis or article publications in academic journals, was also anonymised like described above. Participants were informed about this procedure prior to providing their consent.

Concerning the storage of data, all collected data – including audio recordings, transcripts, list with pseudonyms – are saved on my personal computer, which is a password protected computer, to ensure data protection from any damage, loss, unauthorized distribution or/and processing. Only I, as the researcher, have the password. Paper copies (ex. consent forms) are kept in a locked cabinet at the Department of Psychology of the University of Cyprus and only me, as the researcher, have the keys.

Concerning the time that data will be stored, the General Data Protection Regulation will be followed [Official Gazette of the Republic of Cyprus, 2001, Article 5 (I)(e) & Recital (39)], aiming at the least amount of time for the storing of data. Therefore, the collected data will be kept for five years, which is considered a reasonable time period for data analysis, completion of the PhD thesis, academic article writing and publication. By the end of the five years, electronic data will be permanently deleted from my personal computer and hard copies will be shredded. I, as the researcher will be the only person involved in the destruction of the data.

4.4.2. Non-maleficence and withdrawal

The participant parents of this study were informed in advance that their participation in this research project is voluntary. Participants were asked to give their consent for this research, after being thoroughly informed, retaining their right to withdraw their consent any point of the research process. This information was provided orally but in written form, as well.

Participants were informed that they had the right to submit their grievances and/or complaints to the Research Support Service of the University of Cyprus referring to Dr Marios Dimitriades (page 10 of the consent form, appendix B). They were informed about their right in written, provided full details of Research Support Service and prior to giving consent to participate in the programme.

Additionally, participants were informed and encouraged to address to counselling services in case they felt distressed or any other intense feelings during the interview or the focus group. Details of this procedure are discussed in the consent form (appendix C).

Chapter 5: The milestones of the parenting experience

Parenting a child with a developmental disability involves some important milestones. The aim of this chapter is the in-depth review of these milestones, as they are viewed by parents. Such an analysis is significant in order to approach the parenting experience as a whole.

The experience of disability begins for the parent with the diagnosis. The announcement of the diagnosis is a critical point, introducing parents to a new life-time experience. The first parental but also the long-term reactions to the diagnosis reflect the way in which the parents experience their children's disability. Another milestone of the parents' experience is their interpretation regarding their child's diagnosis, interpreting it as a random event, as their responsibility, related to some superior power or to medical factors. Finally, the parents' experience is approached through the "lens" of others, in relation to the close or the broad family, to friends but also to the extended social milieu. The reactions of others but also the parent' approach towards the others is indicative of the way parents represent and deal with their children's disability.

5.1. Parents' experience of the diagnosis

The diagnostic process might be an immediate one-off announcement of a medical result but it may also be a time-consuming, long-term process that emerges out of various medical procedures. Sometimes there is prenatal testing associated with a diagnosis, but others not (i.e. autism) and the diagnosis may take a while to be completed, possibly until the child's preschool age or later. Another interesting feature of the diagnosis, especially in young children, is that it involves a comparative process, using certain developmental milestones, comparing them with what is considered typical and the distance from it (McConachie, 1995). Whatever the process, the diagnosis consists a significant part of the experience of parenting a child with developmental disability.

5.1.1. Parents' experience of the announcement of the diagnosis

The diagnostic process initiated with the announcement of the diagnosis for the interviewed parents, either in the first years of life or immediately after the birth of their child, except one case where it was known prenatally. The announcement of the diagnosis is an experience that varies considerably from parent to parent, due to the way in which it is announced by the relevant professional but also due to how the parents themselves understand this announcement. Here are some incidents of the diagnosis' announcement, as experienced by the parents themselves.

The mother in the following narrative explains how the way the diagnosis was announced to her by the doctor motivated her to take action and start the needed interventions towards the child:

E. Umm yes, I do remember (…) taking him to a child psychiatrist. (…) The psychiatrist did an evaluation and told me "listen, y*our son has autism. Umm because umm I have seen many similar cases, it's important for you to work with him to help him get better. Okay? Umm I learned a lot from other parents". And then she told me "just know" that "he is eligible to receive government support" and so on. Umm I really appreciated the psychiatrist's approach in telling me. She didn't give me the chance to cry "now what", "now what". Umm what really stuck with me was her suggestion to "work with him because he will get better". (…) She was clear about it. "He has autism". Those were her exact words. (…) Umm that was really helpful for me.*
ED[12] *Hmm … yes.*
E. Others were … (unintelligible), they were angry. (…) Because if she had told me "it's okay … and don't worry", maybe I wouldn't have taken it as seriously. What made me realize this was serious, was her saying "get back up and move on". (…) And that's exactly what I did.
ED. Yes.
E. It depends on how each person handles it. She didn't explain the situation in a hateful way or with… She told me "listen, this is what's going on". Calmly. "This is what's going on".
(…)

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[12] The initials ED indicate the researcher's name.

E. …do you know what the problem was back then? Aside from the child psychiatrist, umm this sugar coating about 'autistic characteristics', but looking back on it, it was clearly autism. (…) She was really straightforward about it. Umm but the way I look at it, was that she was perfectly clear about it, that "I should start immediately (emphasized) so you can, so you will be able to help your child get better". Umm with my personality, if she had told me about it the way the previous child neurologist did, 'autistic characteristics', umm I would still be researching about it. After meeting with the child psychiatrist, I just started doing intervention, educational interventions. ***.*** *Immediately. So I didn't waste any time.*

Elena, mother of a 10-year-old child diagnosed with autism

The mother criticizes the way some professionals present autism to parents, using the generalized term "autistic traits", in an attempt not to shock them. According to her, this results in the parent not realizing the seriousness of autism. In her case, the psychiatrist put it bluntly, clearly, emphasizing that interventions should begin immediately, so she wasted no time for emotional reactions or for further assessment of the child. This way of announcement, appreciated by the mother, worked for her as a clear but with no-panic alarm: your child has this issue and needs immediate intervention.

Other parents report a negative memory about the announcement of the diagnosis. Andriana describes this negative approach of the announcement:

A. What I still remember, is my gynecologist telling me "I'm sorry, Andriana".
ED. So he apologized?
A. Yes. I told him, "please, doctor". Because he apologized and then (…) "I looked over everything again, everything was fine", and so on… I told him, "please, doctor. Don't ever apologize again". "Petros would still be here". I told him, "I would have still given birth to him. Even if you had told me, I would have still given birth to him". "I wouldn't kill my baby". "I would have still given birth to him". He told me "umm that's a really huge relief". (…) The pediatrician, like I said, probably because she's also a woman and… she maybe felt that she should soften the way she approached it, she said "we'll look at the test results from the Institute of Genetics" and so on. Umm … In general, the pediatrician was probably the only one who didn't act as if it was the end of the world. Anyone I visited after that only had bad things to say.
(…)
A. What stuck with me? Umm … I don't really remember anything sticking with me, I told you about the pediatrician because her approach was great. When it comes to the others,

I remember the anxiety. Most of the others weren't exactly saying "he will be unable to walk, he will be unable to speak". They said "he may have heart issues", "he may have this, he may have that". They never said that it was also possible that the child wouldn't have any of these issues, for example. And he is just a happy child. Umm he provides you with love that you've never received before from anyone. That's what no one tells you about. I think that they don't know about it, so they don't tell you about it. (…) Because as I said. They… they didn't tell me anything positive. Only the negatives. Only the negatives and umm … it was my first baby, I was completely inexperienced.
(…)
A. What would have been the best way to tell me? I certainly didn't want them to say "I'm sorry". Umm …
ED. What bothered you about hearing "I'm sorry"? What did it mean to you?
A. Umm it meant that umm "I'm sorry that we didn't find out that your baby isn't perfect and that we let you give birth to him" (…) I think that's what it means when you say "I'm sorry".
ED. It's as if they tell you that the baby himself is the problem.
A. Of course. (…) Not the child itself … its … the child's diagnosis.
Andriana, mother of an 8-year-old child diagnosed with Down syndrome

The diagnosis was announced to the mother by the pediatrician immediately after delivery. The mother appreciated the pediatrician's attitude, which was unruffled, unlike others who presented the diagnosis as the worst-case scenario, conveying anxiety and panic to her. The gynecologist's apology, confirms in a symbolic way the "tragic event" of the diagnosis, as a problematic trait of the child, against the mother's own perception who would anyway choose to give birth to the child, despite the syndrome identified. Besides, the mother finds out positive elements too in her child's diagnosis.

The announcement of the diagnosis as a negative process is confirmed by other parents as well. The mother in the following narrative exemplifies this adverse practice:

ED. How did you find out (…) that Christos has Down syndrome?
M. I gave birth, 15 days went by, we did the karyotype test in Makarios[13] Hospital where I gave birth and we received the results. We were informed about them by Demetriadou.
(…) When I gave birth we didn't instantly realize that the baby has Down syndrome. But

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[13] Makarios III hospital is the Cyprus public hospital specialized for mothers and children.

after looking at him, I realized from looking at his eyes that he has Down syndrome. Because Demetriadou and … Grigoriou came to talk to me … (…) Umm to talk to me about Down syndrome and so on. They came and talked to me, and I thought to myself "this is it, I don't only have to wait for the karyotype test". But I didn't say anything to my husband. Umm when they informed us about it umm… 15 days went by and they told us – we took the baby to the hospital on a Friday and they told us "come back on Monday to receive the results". Marios said "there's no way I'm waiting until Monday". The results were out and we found her in the hallway, asking her to tell us the results and she wouldn't. *Marios told her "I'm not leaving here until you tell me what the results are". (…) So we go to her office so they can tell us the results. Ah … that moment was tragic (smiles). She told us the results and then Marios got angry, and slammed the door behind him as he went outside to smoke. Umm and one of them told me "umm you know, there's a possibility your husband will leave you because the baby has Down syndrome". Umm I thought (nervous laughter) I umm knew, I thought it would be alright, I knew what .. But for Marios it was ...*
ED. Sudden.
M. Yes, that moment … Um okay. It's different to suspect that it's true than seeing it in writing.
E. Hmm. Yes … yes.
M. … "your baby has Down syndrome", and so on. Umm it was awful to hear in that moment that "you know, your husband may leave you now" because he went outside and slammed the door. (nervous laughter) (…) They basically thought "Ah, this guy is gone!"
ED. What did you do when that happened?
M. I stayed there and was berated. They laid into me (nervous laughter).
ED. And did you just stay silent?
M. Yes. I stayed there, I listened to them, I was crying, okay …

Maria, mother of a 6-year-old child diagnosed with Down syndrome

The mother describes her own experience of the announcement, emphasizing on the delay, the disorganized process and the lack of empathy and professionalism. The two parents reacted differently to the announcement of the diagnosis, but both were negatively affected by the professionals' approach. The parents' needs during the announcement were not taken into consideration, on the contrary, the professionals brought up other scenarios that caused additional stress (*"umm you know, there's a possibility your husband will leave you because the baby has Down syndrome"*). Similarly to the previous extract, Down syndrome is represented as a tragic event, that might also provoke issues between the couple. Another interesting finding of this story is the power position adopted by the professionals (*I stayed there and was berated*), power related to their level of knowledge, which again impacted negatively the parent.

An abrupt way of announcing the diagnosis is reported by other parents as well. The mother in the following extract illustrates her experience of the announcement:

D. Umm the neurologist had a large book, I assume that it contained a lot of information, about a lot of syndromes. I don't have that book, but just by seeing it, I remember it also had a picture inside. (…) She opened the book right in front of us. She pointed at a page and she said "this". "This is what your daughter has".
(…)
ED. … what do you now think about the way that the doctor announced it to you?
D. Let me, let me tell you. When you find out that your child has so many serious issues, you hang on to every word (emphasized) of the people who know (emphasized) something more about what they just announced to you.
ED. Yes.
D. So, on one hand you really need them, you feel like you really need them. On the other hand, you are upset (emphasized) at the way they treat you. They're two conflicting emotions.
ED. Mmm, mmm. Yes.
D. And … that need you have for them makes you feel angry. Why would I need someone who doesn't treat me right? (…) And the worst thing is feeling that you need (emphasize) their help, that person's knowledge. And unfortunately, there are not a lot of experts in Cyprus … so you don't really have the option to choose, to … to say I don't want to work with … I mean … to be, to choose that person as a doctor, for example.
ED. Mmm. Hmm, hmm.
D. For example, there are only two developmental specialists in Cyprus.
Demetra, mother of a 6-year-old child diagnosed with Alpha syndrome[14]

Demetra focuses mainly on how she felt when her child's diagnosis with a rare syndrome was announced to her. The professional's knowledge is again a major factor, as the mother felt completely dependent on this knowledge, causing her anger and resentment. Specifically, she emphasizes the non-proper way of the announcement by the professional, non-empathetic, sharp and abrupt. The professionals' behaviour seems to fully determine

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[14] For purposes of confidentiality and anonymity, some syndromes are not mentioned by name. Accordingly, the name 'Alpha syndrome' is used as a pseudonym.

how parents perceive the announcement of the diagnosis. According to the mother, parents do not have enough alternative choices of other professionals in Cyprus, which makes her feel trapped.

Some other parents describe how they felt lost with the announcement of the diagnosis. The mother in the following extract discusses in detail this feeling:

ED. What was your initial reaction when you were first informed of the diagnosis?
E. I felt uneasy … I kept asking. I was making calls, asking everyone I knew in education, so I could learn (…)
ED. So, were you asking what autism is? Were you asking what you have to do? What exactly were you asking?
E. I was asking what, what, what others do in these situations. Umm I went, umm I happened to see other incidents of autism (…) It was all new to me, new to me (…) We didn't have anything concrete (emphasized) so someone could say "alright, you have, your child has autism, umm usually when this occurs you follow this set of steps, umm the children get help in this specific way". Yes, yes, some sort of guidance. (…) Umm everything was chaotic. Umm and I had to hold onto other parents that umm I tried to connect to whatever I could do. I held onto whatever and whoever I could receive help from, to go wherever I could. And what I could do. And … chaos. Chaos. Umm even thinking about it, I can tell you it was a great shock. I didn't know what it was. I didn't know where to go. (…)
ED. Umm what do you remember more vividly about those days? What, what has stuck with you more vividly?
E. The most intense moments were the phone calls I had to make. (…) And it was also the process. You know, another emotionally-draining process. Having to, umm after the child psychiatrist's suggestion, the child neurologist also suggested that he should start speech therapy sessions and that I should also take him to a psychologist. I had to provide background information, and all other information, separately to every specialist ...

Elena, mother of a 10-year-old child diagnosed with autism

The mother describes a chaotic situation where she had to start a blind investigative process, without a particular plan, since the announcement of the diagnosis. As she reports, there is no structured care protocol in these cases, so the parents have to find on their own the ways they are going to get informed about their child's condition and the following steps they need to take. Elena, for example, started calling all people she knew and she thought they might know something about autism to gather information. Thus, apart from her own inexperience, there was also a great lack of guidance and counselling processes, which the mother had to somehow substitute. The procedural deficit also includes the lack of collaboration between professionals, as a result of which she had to multiple report her child's history, a repetitive process that was emotionally draining for the mother.

The lack of guidance and proper processes at the first stages of the diagnosis is emphasized by other parents as well (*D. Because it was like walking in the dark. There was no one to tell us "visit this person", "do this, do that". You see? It was chaos (...) That you don't know how you will, where you will go to get help*). This unstructured and disorganised situation, in addition to the new fact of their children's condition, make the parents feel lost and insecure (*E. I didn't know what it was. I didn't know where to go*) but might also provoke them feelings of loneliness and helplessness.

Other parents focus on the announcement of the diagnosis as a fragmented process. The mother in the next excerpt analyses this problematic process and how it impacted on her:

D. Everyone says their piece. And they leave you, for example, and … It's like you have to put a puzzle together, not only are you psychologically … you feel hurt in that moment. You have to … connect everything you hear from this person, from that person, so that you are able to see the whole picture.

ED. Yes. (…)

D. Umm … umm, yes, but it's really psych… to have them, to do this thing, there's no question. Okay. Umm it's a routine which umm you have to follow. It's just that the, the, the … most traumatic part for a parent that learns that their child has an issue, is that, is that there are a lot of questions and each doctor and specialist gives you one piece of the mosaic.

ED. Okay.

D. And the parent has a lot of questions, you can't, you can't take a sentence from one person, one sentence from the other person … and put them together to create a paragraph. (…) ***For example, I had so many … worries, I felt like I was going crazy with the worries I had and … I don't think that they realized how many issues … we would have to face.*** *I mean … or maybe they didn't analyse them the way I did. But I analyzed things to a point that … I mean umm I wanted to know about … where we would have problems, where we would need support, where we would have to support our own child.*

Demetra, mother of a 6-year-old child diagnosed with Alpha syndrome[15]

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[15] Alpha syndrome is a pseudonym of a rare syndrome.

The mother represents the diagnostic process as a puzzle, where various specialists presented her daughter's syndrome to her, each one from the perspective of his or her specialty. According to her, there is no overall view of the situation, the parent is responsible for putting the pieces of the puzzle together and for coming to a conclusion herself. This adds an extra load to the already burdened psychological state of the parent. Thus, the parents count two probable traumatic experiences, one of the child's diagnosis and one of the ways the diagnosis was announced to them: fragmented, without coherence and without empathy for their own emotional needs. The sense given is that the mother felt left alone with her questions, proved by the special reference to the severity of her concerns (*I had so many … worries, I felt like I was going crazy with the worries*) but also to the lack of understanding and empathy she experienced.

Overall, the parents describe their experience of the announcement of the diagnosis through some shared patterns. First of all, parents testify (i) *a negative memory of the announcement* of the diagnosis, with the diagnosis being represented *as a tragic event*. Additionally, parents experience the announcement (ii) as a *disorganized and unstructured process*, *fragmented and chaotic*. Lastly, parents emphasize (iii) *the non-proper behaviour of professionals* during the announcement, lacking empathy and professionalism, *adopting a power position* which makes them feel dependent and angry. Throughout the process of the announcement and in relation to these patterns, parents report feeling stressed about the unknown, lacking knowledge, and generally feeling helpless concerning their children's diagnosis.

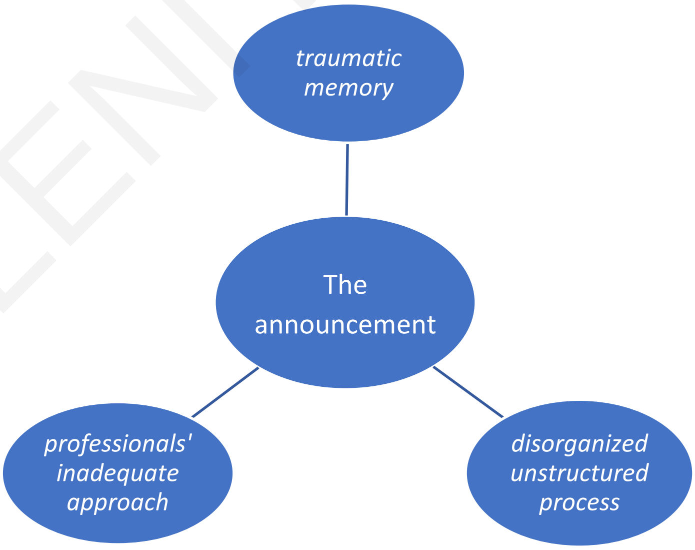

Figure 5.I. The parents' experience of the announcement of the diagnosis

5.1.2. Parents’ initial reception of the diagnosis

For several parents, the initial reception for the announcement of the diagnosis was shock. Even when the diagnostic process took some time, parents reported feeling greatly shocked by the announcement. Parents describe this feeling as being “showered with cold water" (*I. It felt like a cold shower. So, we were … it’s way too … heavy)*, as if they had “lost the ground under their feet” or as if “a bomb is been dropped” in their house (*E. But at that moment … you drop a bomb in a house. You drop it … you leave it there, and leave)*. The father in the next extract exemplifies this initial reaction:

N. Umm yes, it was indeed a shock for us. Because I didn't expect that … the child had any issues (…) We went to the child neurologist, John Simopoulos, who informed us of this and that, “I won’t hide anything from you”, he said, “it is a permanent issue, it is non-reversible”, so, it’s not, “it’s a non-reversible issue”. The only thing the child can do is occupational therapy, speech therapy, and all these can help the child’s condition improve. It's clearly a matter of improving now.
(…)
ED. When Simopoulos told you that “you know, it’s a permanent issue”. How did you feel?
N. (takes a deep breath) As I said, I thought “there are difficult years ahead”. Of course, I felt disappointment, I fell to pieces. It felt as if the sky was falling. (…) Umm … But as time went by … we understood more and more that this, this (emphasized) is what we will move ahead with.
(…)
ED. What did you do in the following days?
N. I isolated myself somewhat. (…) Yes, I took a 10-day leave from work during that period. I withdrew into myself, I didn't speak, I didn't eat … until I understood it. Because … as I said at the start, it was a shock.
Nicolas, father of a 5-year-old child diagnosed with congenital brain disorder

For Nicolas, the announcement of the diagnosis felt like an immense shock for him and his wife, since they did not expect it. The permanent nature of the disorder was at the core of the frustration he experienced. The father needed some time to himself to absorb this announcement, time which helped him to better understand the situation and surpass the initial shock.

Similar shock is reported by the mother in the following narrative:

ED. Umm … when you first heard this umm the diagnosis, what was your initial reaction?
T. I umm … my world turned upside down. I was sad. In all honesty, I was shocked, I was lost. Umm I was mourning. Umm I went through … yes, and then I was … I went, I had no idea what autism was, I went online, read about it day and night, read articles, to understand what it is. You can't, umm … umm, yes, I couldn't accept it, I was angry later on, "why?" Umm … "Why is this happening to me?" It was my complaint.
(…)
ED. Umm …when the educational psychologist informed you about it, what did you understand?
T. I understood that my child has a problem. That's what I understood. I considered it a problem. (…) My world turned upside down. Sorr, umm …sorrow. "Why did this happen to me?"
ED. Yes. Hmm ... yes. There were unanswered questions …
T. I didn't think of my child. I thought of myself. At first.
ED. Mmm, hmm. What do you mean by that?
T. Umm I mean that … in that moment, immediately, that for example umm …I felt sorry for myself. Why did I have to experience this? Umm but now, I see more clearly, that, that umm … now I think of my child as well, that he faces difficulties, of course, but in that moment … I don't know, maybe I thought, I'm not saying, maybe I thought of my baby as well, but I remember my own experience more vividly.

Theodora, mother of a 6-year-old child diagnosed with autism

Theodora reports feeling lost, sad and shocked with the announcement of her child's autism. She, then, remembers having mixed feelings like denial, anger and in need to learn more about this unknown for her condition. Her initial reaction was questioning why, focusing totally on her own emotional experience and feeling sorry about herself. In fact, she confesses this strong experience with a sense of guilt, as something selfish for a mother who must constantly focus on her child. Here, as well, autism is primarily represented as a problem, as a negative trait of the child.

The concept of death is a shared one, which recurs in parents' accounts of the diagnosis. Demetris, in the following extract, resembles the reception of the diagnosis of autism as the loss of his child:

ED. How, do you remember how you felt those days, when you were informed of the diagnosis and you had to start all these things? How were you?
D. Hehe (smiles), how would I feel? As if I had lost my child. As if I had lost (unintelligible). Exactly this way.
ED. Mmm. Umm …
D. It was a, it was a huge hit (…) What, pff (sighs) what's there to remember at this point? Umm it was as if everyone in the house was in mourning. It was really hard. Umm it was really hard.

Demetris, father of an 11-year-old child diagnosed with autism

The announcement of the diagnosis is represented by the father as the loss of the child, experienced by the family as bereavement. The way the father describes it, brief and thrifty, depicts the representation of mourning, as he doesn't want to say more. It was a very hard time for their family, a big hit, which made him feel devastated, similar to one's experience of losing his/her child.

Other parents describe in their own words this enormous for them loss, like a traumatic event that they might not recover from (*D. Eleni, I felt really awful, that feeling … And I still don't, I don't know if I will ever get over it (cries). It's as if … I lost my child (cries) (…) I feel that someone umm … someone stole my child, someone took my child from me. And I don't know why, I feel as if I lost her / E. Umm … I thought that someone put a knife here (points at her chest) and twisted it like this each time. Or … (…) it took her two months to say 'mum'. This felt like death to me).* The announcement of the diagnosis is likened by the parents with the possible announcement of the child's death. The parents feel a huge loss, which is obviously related to the loss of the healthy child and their expectations about it (further discussed in chapter 6.1.5.).

Similarly, the mother, in the following extract, discusses her mourning phase:

A. I remember reading Mr. Christodoulou's[16] report many times. I would get up at night, before going to sleep, to read it again.
ED. Before going to sleep?
A. Yes. Or I would have an idea for example, I would take a picture of the report, I saved it in my phone, the picture, and I read the paragraph over and over again (unintelligible).

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[16] Specialized doctor from whom they asked to assess their child at the very beginning.

ED. Yes.

A. I don’t know, so I could comprehend it?

ED. So you read that one paragraph …

A. The conclusion again. In conclusion.

ED. And what … how did that help you?

A. It didn't … it didn't help me. I don’t know, to get my head around it? (…) I think to get my head around it.

ED. Yes, to get your head around it.

A. Yes. Or to mourn about it. Because I mourned.

ED. Yes.

A. I think it was this (unintelligible). It was mourning.

E. Yes. Hmm, yes, yes.

A. I think that’s the first stage. I have read that that’s the first stage that the parents go through. You mourn.

Antonia, mother of a 6-year-old child diagnosed with autism

Antonia describes how she obsessively used to read again and again the conclusions of the medical report, which officially signified for the first time that her son had autistic traits. She appears to reflect about the target of her obsessive behaviour but concludes that it was a manifestation of the mourning she experienced. For her, it seems important to highlight the fact that she went through bereavement, stating it repetitively (*Or to mourn about it. Because I mourned. (…) It was mourning. (…) You mourn).* To support this statement, she notes that she studied about the stages of grief, which lends additional validity to her experience. For the mother, confirming the mourning is an indirect confession of the pain she experienced, like when someone is mourning.

All the above stories share the context of the tragic experience, either through mourning (Antonia) or through the symbolic loss of the child (Demetris), which parents feel they might not recover from (Demetra).

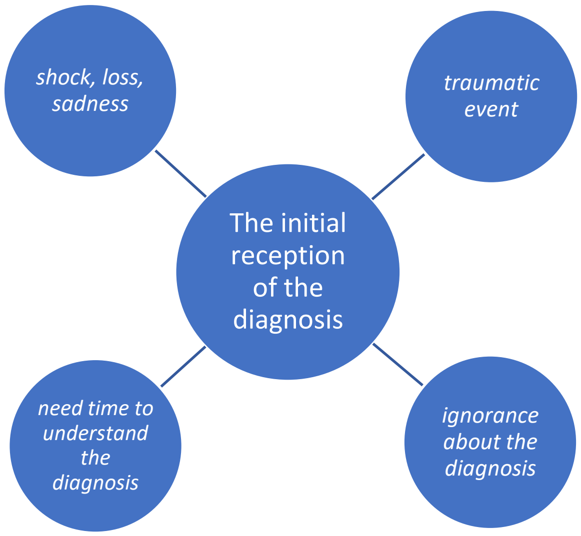

Figure 5.II. The parents' initial reception of the diagnosis.

The announcement of the diagnosis and the understanding of this announcement are placed at different points in time by the parents. Parents have little or no understanding of the diagnosis when announced to them. This occurs because of the way of communicating the diagnosis but also because of the parent's level of knowledge about the diagnosis. How and when parents comprehend the diagnosis is another topic well discussed during interviews. In the following group interview, mothers argue their level of information about autism when they got their children's diagnosis:

E. Umm okay. Umm … Umm basically me … when it was announced to me, I didn't know a lot. I mean, okay, only the basics. I thought that autism meant those kids you saw that … I don't know, those who have severe autism. *(…) I started reading about it. I wanted to educate myself, I wanted to know everything about … about the spectrum. And I didn't start that process, I don't think I let myself. Okay, there was crying. Beating myself up, yes, that's a given. But I don't think I left much room. I wanted to immediately start …to, to educate myself, basically. So I would be able to help my child.*
An. Can I ask you something, Evangelia? Ummm … where did you go to read about it, did you just go on Google, for example, and searched about autism?
E. No, I always visited more …
An. Which one, did someone tell you?
E. No. I always knew that I shouldn't be reading. I had to, I always visited, I always got information, I mean whatever bothered me, I visited more …
ED. Specialized.

An. Did you visit a specific site? Because I did the same too, and at first, I panicked when I searched.

E. I visited, firstly, I visited the associat, the ... associating?

ED. Autistic Association.

E. Yes, for people with autism. I started from there.

An. I didn't even know that existed. Okay, you went the right way. (...) I never did, because, truth is, it took two years to receive a diagnosis for Gregoris. I searched for autism online and I thought to myself "my baby doesn't have this". I didn't know that there is a spectrum. I didn't even know the word 'spectrum', I was completely uneducated. Hehe. (smiles) And ... I also didn't know who to ask. And, you know, I didn't open up that much to ask, it was something that ... And I searched the internet and scared myself even more, and just turned it off. Until I ... Umm ... Dr, Alexandrou showed me something, when the diagnosis was completed, two - two and a half years ago, umm ... she showed me a clip, a video, and I understood so much from that. But I lost that video afterwards. And I can say that I understand much more in the last one year. Umm ... And I'm, it's within ... I'm a molecular biologist, I have a degree in molecular umm ... Using molecular genetics to study diseases, it's part of ... it's part of my field. And I couldn't find, I couldn't ... cope. I did everything I needed to, practically, everything they told me to do for the baby, I did it. Everything. But it took me some time to understand and learn more, and I can even say that I am only now learning most of the things I need to learn.

Evangelia & Anastasia (group discussion)

The mothers here recognize that they didn't know much about autism when they got the diagnosis and that they felt the need to learn as much as they can about it. Interestingly though, not all mothers did this successfully. Specifically, Anastasia describes how she was feeling not able to understand her child's diagnosis for a long time, which she did only recently. The source of information seems to be decisive, whether for example from an organized group or from a specialist professional. The paradox according to her is that despite her professional knowledge on molecular biology and genetics she could not sufficiently understand her son's diagnosis. On the contrary, Evangelia, not having this professional knowledge, was able to choose information resources more wisely, process information and understand the diagnosis, without intervening feelings that would prevent her from doing so.

Apart from the parent's resources, an important point that this quote highlights is that parents need time to understand the diagnosis. This time may include observing the child, searching or even processing information. However, in this case too, the parent is left alone to learn and gather information about what the diagnosis of the child is. There is no official or professional information, except at the request of the parent herself, as discussed in chapter 5.1.1.

The parents' initial reception of their child's diagnosis is summarized in certain patterns of findings. At first, the parents experience (i) *intense shock* with the announcement of the diagnosis, reporting feelings of loss and sadness. Several parents described their initial reaction to the child's diagnosis as *bereavement*, likening the diagnosis to the *symbolic loss of the child*. The child's diagnosis is also experienced (ii) as a *tragic and traumatic event* that leaves an indelible mark on the parents. The majority of parents claim (iii) *ignorance regarding the diagnosis*, which they need to explore on their own. Finally, another essential (iv) *need for parents is time* to understand their child's diagnosis.

5.1.3. Parents' long-term reception of the diagnosis

During the interviews, parents discussed their long-term consideration but also their level of acceptance regarding their children's diagnosis, which seems to include several processes and reactions. This long-term reception of the diagnosis is different for every parent, experienced in a personalized way, influenced and determined by each parent's approach.

Three main patterns of long-term reaction came out of the parents' narratives: (i) parents might *accept their children's diagnosis*, (ii) *not accept it* or (iii) *keep some distance from the label of the diagnosis.* However, the acceptance of the diagnosis might be experienced and represented by parents in several ways: as a *no-choice process,* as a *grounding to the reality of the diagnosis*, as *competitive to the effort needed* or as a *process of acceptance*.

Some parents illustrate *acceptance of the diagnosis* as (i) *a one-way, compulsory process, like there is no other choice*. Eleftheria, in the next extract, exemplifies this approach:

ED. Do you think you have accepted it?
(short pause)
E. I don't know how to tell you this.
ED. Okay, hmm … it's more about recognizing the issue …
E. You don't have a choice though.
ED. Yes.

E. What? To not deny it? How? Do I have a choice? Considering …
(…)
E. Okay, after a certain … (…) After a certain, after a certain age, okay … after … Okay, after a certain age, what, do you want …? Umm it's crystal clear what the child has.

Eleftheria, mother of an 11-year-old child diagnosed with autism

The mother reflects openly about the acceptance of her daughter's diagnosis, concluding that it is a compulsory process and not a choice for the parent. She also brings out the factor of the child's age as decisive to this obligatory process of acceptance.

Some parents focus on having no choice regarding the acceptance of their children's disability. Similarly, Athina claims that the parent has no choice of accepting the child's disability or not (*A. Okay, you don't even have a choice*). Demetra focuses on the coercive nature of her experience, describing how she wouldn't want to but she is obliged to experience it since there is no other choice for her (*D. … I am in this situation 'through fire and iron'. (…) Everything that happens is due to necessity*).

Some parents describe *acceptance* (i) as a rough *grounding to the reality of the diagnosis*, as an abrupt reconciliation with the idea, which happens once and for good. Georgia in the following narrative exemplifies this approach:

G. Basically … basically, I just came down to earth … approximately in the past year. Earlier, I believed that he would lear… he would be capable of talking… I even believed that he would learn how to read and write the letters of the alphabet. I came down to earth during this last year.
ED. Hmm. So, what do you now realize about…
G. That it's really… I don't know if he will become able to speak yet. If he even speaks… I know that he may not become able to speak in sentences, but only with words … so I accepted it. When I first learned about it, my only concern was him talking… I was under the impression that only verbal communication existed. That's what I thought… that's what I thought… that the only way two people can communicate was verbally… Umm when we started using pictures and I saw that we can communicate, I started to forget that he is unable to speak. I now don't care that he is unable to speak.

Georgia, mother of a 5-year-old child diagnosed with autism

Georgia describes her *grounding to the reality of autism* as a result of adopting more realistic expectations regarding her son's development. The mother also emphasizes on the importance of knowledge, how for example the use of alternative forms of communication helped her to interact with her child with autism and to see beyond the usual expectations of development.

This compromise is different from parent to parent and may concern several issues of the child's functionality. For Nicolas, this is about the reconciliation with the idea of the child never being fully independent (*We now understand that there is a chance (…) she won't ever become fully independent. But we have now learned to live with it. Okay, we have made peace with it*). For Antonia, the conciliation is about not asking from the child things that he cannot do (*It was his birthday yesterday, and on previous birthdays I pressured him to stand up and blow the candles. Yesterday I thought "but he is unable to do it" (…) I have accepted that he is unable to stand. Whereas two years ago, I used to cry (…) Isn't this acceptance?*). This is about a reality check with more realistic expectations regarding the child's potential, but also about the unconditional acceptance of the child as it is, with their difficulties, regardless if they accomplish the parents' expectations. All parents agree that this compromise leads to acceptance (*I'm getting somewhere. I still have a long way to go, but I think I've lowered my expectations too*).

Other parents discuss *acceptance* (i) as competitive to the effort needed. Vasilis' way of thinking is a good example of this consideration:

ED. I wanted to ask you if you think that you have accepted … Anna's difficulty (…)
V. Look. Accepting it means you don't do anything to change it. Since you are trying to, to change things for the better, you can't say that you accept it. You … you accept it up to a point, that is … this is the road we are on, it's not that one (points with hand). But if you say that you accept it, it means you're giving up.
ED. Yes. Okay, maybe …
V. You think that … Anna is like this. End of story. And I move on with my own life. That's what will happen if I stop, if I think that Anna will always be like this (…)
ED. Maybe I didn't phrase it right. Someone may say that "okay, I accept that my child has these issues. And I'm doing these things to help".
(…)

V. Look. I know about Anna’s issues. And I’m trying to do my best. Umm whether things change or not, doesn’t, doesn't always depend on my effort. (…) Umm so umm … I fully understand the reality of the situation.

Vasilis, father of a 6-year-old child diagnosed with autism

For Vasilis, acceptance implies a compromise, an abandonment of the effort, with the child remaining at the same point of development, without improvement. On the contrary, the continuation of the effort, which he chooses, means not coming to terms with the present situation and hoping for the best. However, for this effort to be accomplished it is necessary to recognize the child's difficulties, which he has achieved. According to him, acceptance cannot coexist with the effort to change. Acceptance means not giving up the attempt, but acknowledging while adapting to the difficulties and trying to do the best out of the available resources.

Similarly, Eleftheria represents *acceptance (i) as competitive to the effort needed*, as if someone accepts and compromises with the child’s difficulties as irreversible:

E. Umm … but I don’t know how to, what it means to accept it (very reluctantly). That this is it, this is my daughter and that I love her, yes.
ED. Yes.
E. I certainly wouldn’t have wanted her to have autism. I don’t know if I have accepted it yet. I don’t know what that means exactly. So, what do you do if you accept it? Do you accept that your child is not in the classroom but in a different unit? Do you accept that your daughter won't ever be capable of showering on her own, and you don't try to improve that aspect? If that’s what acceptance means, umm no, I haven’t accepted it, because I want to make an effort to improve these things.
ED. Okay.
E. If acceptance means something else, I don’t know what the meaning of acceptance is.

Eleftheria, mother of an 11-year-old child diagnosed with autism

The mother firmly states that accepting the diagnosis means making a compromise with the idea that her daughter will not develop. Mentioning actual examples, she wants to emphasize that she does not accept the consequences of her daughter’s autism – namely the exclusion or the difficulty of selfcare – and continues the effort to reverse them. It is interesting, though, the way the mother presents her child (*that this is it, this is my daughter*), with a sense of objectification.

Vasilis and Eleftheria in the last two extracts represent acceptance of the child's disability as competitive to the effort. If you accept it, you stop trying for the best of the child. Therefore, their sense of acceptance indicates the desire for change and the effort for continuous development of the child's capacities – not the difficulty of accepting the diagnosis in terms of denying it. The parents who discuss acceptance as competitive to the effort also introduce a doubt about what acceptance means (*E. … I don't know what the meaning of acceptance is).* Similarly, Marcos argues on this 'competitiveness' between acceptance and the effort needed, which feels for him as a motivation to continue this effort (*M. I don't think it helps me … I believe that it's a thought that leads to inaction. And to anxiety. I mean, okay … I don't think that accepting it will make me do anything more. (…) I don't … in reality, not accepting it makes me more active, in a way …).* Both Eleftheria and Marcos appear to firmly believe that they do not want the compromise of "acceptance" and they prefer to put great effort to change the child's condition.

Other parents also adopt the attitude of the effort but from a different starting point, namely parents who represent *acceptance as a process* (i). Those parents discuss acceptance as a long-term, complicated and not linear process, which needs time. The mother in the following extract explains in detail this process:

C. To tell you the truth (…) every time you think that you have accepted it, you notice something new … and whenever you say "okay, here's another aspect that we must … must… accept, or face and come to terms with". I had realized that I have a child with autism. When I came to Cyprus, and Antonis exhibited a severe autistic profile, I realized it. Even though Antonis came here when he was five? Five and a half? I thought "okay, I have a child with… autism". But… here…
ED. When the most difficult of it was over.
E. Yes. When he came here, I experienced the most severe version of it, and I understood what my child's autism means. He made life a living hell (laughs) … And now I have reached a point where I think that I accept it, that's why I'm telling you that there are different phases, that not everything is under my control.
ED. Mmm.
C. When it comes to the child and his autism. Up until now, I knew that I could shelter him, I could save him, I could do this, I could do that. Now that we get exposed (…) the kid

himself is exposed to the tough social life of (…) primary school, God help us. Well, umm… now I need to accept that I can't shelter him everywhere. And control everything. That's really hard, Eleni. (…) Because up until now, things were under control, and you say "okay, we're good, I got this". And suddenly, you move to a phase where "no, you don't control this. You don't control this now. And now?" Now I need to be able to accept that he will come back and feel hurt. And that it is up to me to find a way to heal this. Me and his team, certainly me leading the way as a mum, will be the first to see (…) So there are different levels.

(…)

C. I think it's two… umm it happens simultaneously, Eleni. (…) It's a process, but besides that, recognizing the issue and accepting it happen in parallel. That is, you recognize that there's an issue and simultaneously, in the last 4 years, after receiving the diagnosis, the realization settles inside of you that we have a problem.

Christina, mother of a 7-year-old child diagnosed with autism

Christina reflects on every small realization, depending on the current challenges she has to face. The family moved to Cyprus 2 years ago, a transition that triggered adjustment difficulties to the child. According to her, acceptance at that time was about realizing that she can't control everything related to her child. Thus, there are several stages of acceptance, directly related to the parent's feelings. Acceptance is not one-dimensional, as it includes coming to terms with these challenges, recognition of the problem and finally accepting, processes that occur in parallel and need time.

Similarly, some parents emphasize on acceptance as a gradual process with many ups and down. Demetra represents acceptance as a multi-beat cardiogram (*… it is a cardiogram (…) It cannot be a straight line. It must have constant ups and downs*). According to Marios, acceptance is a process negotiated by parents with no back but only forth, a process of acceptance which can't be undone (Erm, from the moment you accept it, you start working on that thing you already accepted. You can't take it back). Some other parents, such as Yiannis, highlight the changing nature of acceptance, as something that takes time (*It's ongoing [word said in English], it's ... indeed a process that ... um takes time*). According to the parents, time is an important factor in the process of acceptance, as accepting the diagnosis seems to change as life circumstances and conditions change.

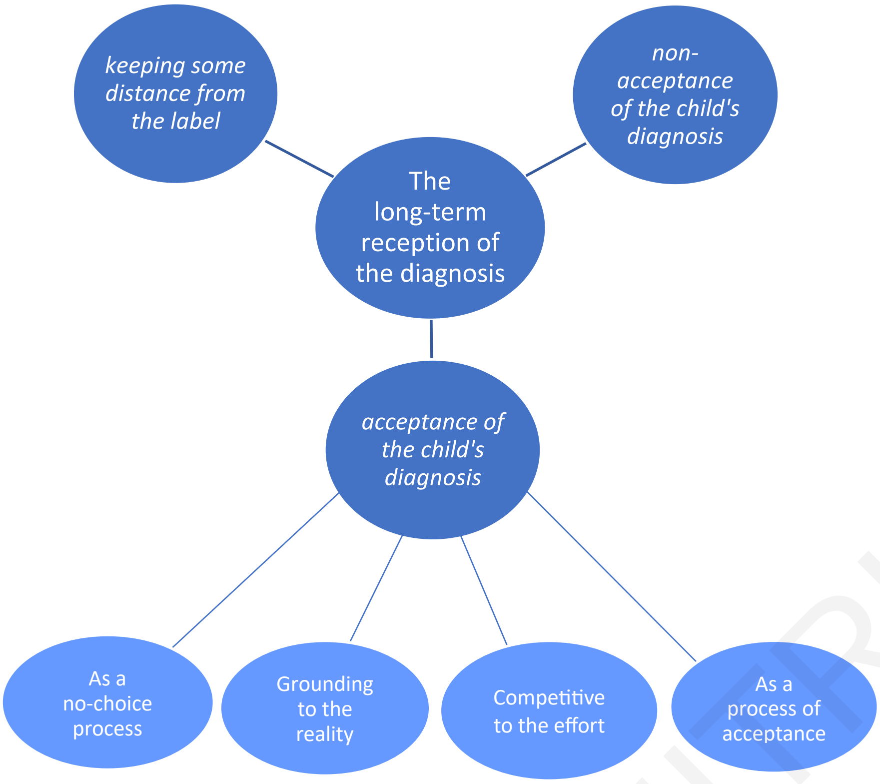

Figure 5.III. The parents' long-term reception of the diagnosis

It is interesting that these two approaches of acceptance, acceptance as competitive to the effort and acceptance as a long-term process, have a direct impact on the way the parents function and on the effort they put regarding their children's difficulties. While the other forms of acceptance are more 'theoretical', they might not influence directly the parents' action. For example, acceptance as a process also implies an effort on the part of the parent who tries to realize and find solutions for the child's difficulties. Whereas acceptance as a no choice, as a one-way progression, seems to locate acceptance as being outside of the parents' control.

Other parents state openly *that they have not accepted their child's diagnosis* (ii). Theodora in the next narrative exemplifies this perspective:

T. (…) I haven't shared this yet, that … I am still hiding it. I didn't mention that my child has autism. I haven't worked on myself yet umm to reach a point where I can say umm that my child is on the autism spectrum. Umm something that I must (emphasized) do, I feel like I owe that to my child. But I haven't reached that point yet. (…)
(…)

ED. Umm… are you proud of Petros?
T. Ah (takes a breath) … umm to be honest, no. Not yet. I don't feel proud of him because I haven't … accepted it yet, Eleni. That's why. (…) I do believe in his capabilities … but still. Although I should, I definitely should feel proud of him. I don't, umm … I just haven't gotten my head around it, I haven't accepted it. Umm but umm … I don't know how to say this, it's a little bit weird. I mean, this has to do with me, it's not that … (…) No, I haven't accepted it yet.

Theodora, mother of a 6-year-old child diagnosed with autism

The mother discusses about acceptance, as something she hasn't achieved yet. Not discussing about it openly is a sign of non-acceptance to her, with important consequences, like not feeling proud of her son. Acceptance is an inner process of self-development (*I haven't worked on myself yet),* concerning exclusively herself, which she sets as a future goal.

Lastly, some parents seem to *distance themselves* from the label of the diagnosis (iii). Alexandros in the next extract exemplifies this approach:

A. I don't bother thinking 'why is Philippos like this?' I don't let it consume me, keep me up at night, thinking 'why is Philippos like this?', or 'what went wrong?', 'what, what have I done?', (…) I mean, I've to told you this many times in the past. Philippos is Philippos. He just is like this. That's it. [said in English] (…) Yes. There … there isn't, there is no reason (emphasized) to bargain with yourself about something that is out of your control.
ED. And something that is a fact, from what, from what I understand you're saying.
A. It is for me, yes. I take it as a fact [word said in English]. I see it. It's in front of me. Philippos is just the way he is. Now, whether that's called autistic, umm low-functioning, medium-functioning, medium, high-functioning, Asperger, on a spectrum, or not, that's gone …
ED. I understand.
A. ADHD. It doesn't matter. All these labels mean nothing. I see that Philippos is this thing … (unintelligible) with a particularity. Good. This is it. No problem. We accept it. I accept it. Philippos is like this. End of story.

Alexandros, father of a 6-year-old child diagnosed with autism

Emphasizing on the importance of not questioning why, which troubles the parent, the father explains how the ‘labels’ of several developmental disorders do not really matter. Besides, the father seems to keep some distance from the label of his son’s diagnosis, which perhaps indicates another process of relating to this diagnosis. This process is neither acceptance (i) nor non-acceptance (ii), it is a king of distancing (iii) from the label of the diagnosis. While discussing his sense of relating to the diagnosis, the father also seems to objectify the child – like Eleftheria did in a previous extract (*that this is it, this is my daughter and that I love her, yes*) – as being exclusively defined by his diagnosis: he is the diagnosis (*Philippos is this thing … with a particularity)*. Besides, it is also interesting how the father discusses such an important thing quite theoretically and almost in an emotionless status: “that’s how it is, no problem, we accept it”.

Vasilis also discusses the label of the diagnosis as not important to him: “*Since it was a vague word … it doesn’t actually change anything important. You have a baby. Which you can see. And you don’t know what’s wrong with her. And you go to a doctor who tells you ‘she’s on the autism spectrum’. The diagnosis doesn’t change anything. And that word doesn't help you (…) The words ‘on the autism spectrum’ leaves you hanging (…) And you can’t, you can't, you can’t say ‘ah this is what my baby has’. Or ‘it may be this’ (…) Umm … that vague word practically deactivates you as a parent. You can't help your baby”.* The diagnosis of his daughter with autism is not defining or useful to him, instead it is a hindrance as it seems to prevent him from helping his child.

Overall, the parents describe their long-term reception of the diagnosis through three main patterns: *accepting (i), not accepting (ii) and distancing (iii)* from the diagnosis. However, the acceptance of the diagnosis is represented in several ways by parents. Firstly, some parents discuss *the lack of choice regarding their level of acceptance*, like they can’t help but accepting it. Other parents describe *acceptance as a hard grounding* to the reality of the diagnosis. Some parents discuss acceptance *as competitive to the effort* needed for the child’s development. Lastly, some parents report *acceptance as a process* related to life conditions and to the factor of time. Apart from acceptance, some parents acknowledge that they have not accepted their child's diagnosis and that they need to process this new condition. Finally, other parents keep some distance from the label of the child’s diagnosis, as if the diagnosis doesn't matter.

5.1.4. What helps parents' acceptance of the diagnosis

A central discussion during interviews was about the elements that help or would help parents' acceptance of their children's diagnosis, specifying several factors that contributed to acceptance. The fact that developmental disability (i) *is a shared problem* and the (ii) *realization of the child's difficulties through time* seem to have helped parents process their children's issues. The (iii) *comparison with the worst-case scenario,* the (iv) *negotiation of the label of the diagnosis* but also the (v) *appropriate state or professional support* were as well determinant factors in accepting the diagnosis.

Many parents describe their children's disability as a *shared problem* (i), which concerns other people as well. The mother in the following narrative exemplifies this understanding:

ED. What helped you reach this stage?
M. Look. The seminar we did together, for example, helped me. Before that …
ED. The parents' discussion group.
M. The parents' discussion group.[17] *Where we discussed, where I listened to other parents, their experiences, the fact that …*
ED. You listened to other parents.
M. Yes. Listening to other parents helps me. They helped me so much … (…) to reach this stage. What also helped me was the support from other parents, when we talked, such as when I have a problem and I call a woman who experiences something similar, she will instantly understand what I'm saying and she will give me advice.
ED. Ah I see.
M. But she will understand me. "Yes Marina, I know, that's what my child was doing to me as well".
ED. Sharing.
M. Yes, that's it.

Marina, mother of a 9-year-old child diagnosed with developmental disabilities

The mother describes how sharing helps her to accept her child's disability. The core feeling experienced, through this sharing, is not feeling alone, giving her a sense of relief. This feeling is illustrated by Georgia as well in the following extract:

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[17] The mother is referring to parents' discussion group, which preceded the particular individual interview.

ED. What helped you accept it?
G. The fact that I'm not alone, that there are a lot of families like mine (…) If … It was only me … it would certainly bother me more (laughs).
ED. You'd feel more weight on your shoulders.
G. Yes. But after I met so many families... well, okay... I'm not alone.
Georgia, mother of a 5-year-old child diagnosed with autism

According to Georgia, sharing contributes significantly in accepting the diagnosis, since she stopped feeling isolated or feeling the disability as her individual problem. Additionally, sharing gives her the sense that she is not alone, strengthening her hope through the "living examples" of other parents.

Another factor that helps the parents in processing the child's disability is (ii) *the realization of the child's difficulties through time*. The mother in the next excerpt discusses this process:

I. (…) the child neurologist told us "it's cerebral palsy". Really straightforward about it. But I umm ha (nervous laughter) I didn't really understand what cerebral palsy is. I didn't understand. (…) Umm … But it took me years. It took me so many years (emphasized) to understand that, Nayia's issue. Umm I wasn't, I wasn't ready umm to accept, to understand that Nayia has disabilities. It's difficult to understand, or how should I say this. Umm … I don't think any parent, any person wants to have a child with disabilities.
(…)
ED. Umm many people say that acceptance is a … big process, it takes time. It's not as if you can say, you know, I have accepted it today and that's it.
I. Yes.
ED. It takes time. Do you agree?
I. Oh yeah. For me, yes. It took me a lot of time. Yes, I agree. You can't … When the child neurologist told us 'cerebral palsy', umm … you are not ready, you don't understand it. First off, you can't comprehend Nayia's issue. You can only understand it as Nayia grows up. Then you realize how big of an issue it is.
ED. So it takes time.
I. Moreover, Nayia is changing. Umm yes, it definitely takes time.
Irene, mother of an 11-year-old child diagnosed with cerebral palsy

Irene focuses on how long time it took her to understand her child's diagnosis. The mother admits that initially she did not comprehend the diagnosis by its announcement. Besides, she did not feel ready to understand and accept the child's diagnosis and the difficulties involved. Thus, the required time is primarily related to the parent's psychological readiness to accept the child’s diagnosis, a diagnosis which is undesirable for any parent according to the mother. Time reveals the "signs" of the diagnosis on the child itself, forcing the mother to gradually process, to let the idea of the diagnosis settle in her mind but also allow to understand the severity as well of the problem.

Similarly, some parents discuss how the child’s difficult behaviours contributed in realizing and accepting the diagnosis through time. The mother in the next narrative explains this understanding:

ED. What do you think helped you to… okay, you mentioned the different phases, but what do you think helped you accept it?
(…)
C. Also, the big crises, in which this thing could not objectively be anything else. Because you know, sometimes he tells us that “he doesn't have it”. But when, for example, Antonis comes here and he was another child, he couldn't even speak, he couldn’t even converse, to … he put us, oh my God, oh my God, I don't even want to think of the previous year. This, the … when you see the issue exacerbated this much, then it obviously means something is wrong. You probably have it. Well, I have a child with autism.
ED. So it’s a little bit… you need to experience it, you don’t have…
C. Well, yes, in the end. You don’t have much of a choice… (…) And I’m telling you, for me, the biggest component was the crisis Antonis went through when we came here. I mean umm… okay, that was the beginning of us realizing that something is wrong, like I told you at the start. And after that, there was a great change (…) of our behavior, of the way we were acting that first year.

Christina, mother of a 7-year-old child diagnosed with autism

The mother has found at times herself doubting about the diagnosis. Besides, when she experienced her son’s intense behavioural crises, she confirmed his diagnosis. The crisis occurred when the child experienced a major transition (change of residence) with a huge impact on the manifestation of his autistic traits, which by extension affected his interaction with everybody around him. Thus, the life with the child and the awareness of the child’s difficulties, through his behavioural crisis, contributed in the mother's realization of his diagnosis and, gradually, in the acceptance of her child's autism.

Another significant factor that helps parents accepting the diagnosis is (iii) *comparing with the so-called worst-case scenario*. The father in the following narrative exemplifies this reasoning:

M. Umm another incident happened that, I don't know, it may sound awful … not awful. Hmm it made me feel better, after I saw what other parents who have kids with disabilities go through … Much more severe disabilities than Down syndrome. (…) I'm talking about a 12-year-old child with cerebral palsy, having epilepsy episodes three times a day. While talking to the child's dad, he showed me a video of his child having a seizure while she was in bed. A 12-year-old girl, 1.50-1.60 meters tall. So … Her dad pulled her up like this, had her sit up on a chair, he fed her, wiped her, and the child could only do this (shows a faint smile). Smile this much.
ED. Yes. Yes, yes.
M. Nothing else, no other reaction. So … You could see that they picked the child up and she still had seizures while in bed. I could only stomach to watch three seconds of that video. I asked him to turn in off. After experiencing this, I told to myself, "these parents truly are heroes". What do we do? We just take Christos to therapies.
ED. Yes. And he plays all day.
M. Exactly!

Marios, father of a 6-year-old child diagnosed with Down syndrome

Marios, father of a 6-year-old boy with Down syndrome, makes a comparison, classifying the better and worse type of disability according to the severity of the diagnosis and the degree of dependence on the caregiver. The father concludes that his own child is in a better position, a conclusion that helps him feel better. The father here seems to separate his position from the role of the heroic carer of a child with severe, according to him, disability, adopting a relatively "normal" parenting role. The separation between normal and non-normal is quite obvious in this narrative.

Similarly, Eleftheria discusses the comparison with the worse-case scenario in the following narrative:

ED. Umm … Does the concept of hope exist anywhere inside of you, in your mind?

E. Umm just a little. It's minuscule. I try to, if I was to think of the concept of hope, I need to simultaneously think that there are families that have two kids with autism. So what will these people do?

ED. So you think of something worse.

E. Something worse. Or there's a family with a child in a wheelchair, that child will never be able to speak, never … Therefore, if I think of the worst, I will tell myself not to be ungrateful and have … more hope.

ED. Okay. Yes.

E. But it's in human nature to … focus on your own problems. But when I'm feeling blue, I'll think of that. Which may be a little selfish, it's not right. Umm but it's the only thing that 'helps' to, to encourage you to… And I want to be well for Sophia, I mean, if something happens to me or … or if I get sick in the future … (...) What influences me to change my way of thinking a little, to see things more positively, is to think of worse situations. Or that no one knows what tomorrow will bring. Or I may read in the newspaper that 22-year-olds die in accidents. Umm I'm not doing it…I don't enjoy doing this. Do you understand?

ED. Yes.

E. It's just that I have this …

ED. You make a connection … that …

E. Yes. That yes, I may live with this, but that mother who has lost her 22-year-old son for example, how will she be? (…) This will affect me a little, it will be a wakeup call.

Eleftheria, mother of an 11-year-old child diagnosed with autism

In addition to the severity of disability, the mother compares her situation to a family with two children with autism, where she believes there is twice the problem, but also with the loss of the child, as the ultimate suffering for a parent. This comparison makes the mother feel she is in a position of privilege.

Another way that seems to help parents understand the diagnosis is the way they (iv) *negotiate the label of the diagnosis*, either by emphasizing specific elements of it or by fitting the child's diagnosis into a broader category. The mother in the following extract explains this view:

X. Even the child psychiatrist we visited afterwards, truthfully, didn't … didn't mention that word. She said that he exhibits … behaviors that fall within… and that we should wait a bit

more because he's still young and so on. So that's where the word 'autism', yes … when he was approximately three and a half-four years old.
(…)
ED. How did you feel when you heard that? That Panayiotis is on the spectrum. Barely.
X. Yes. The … the… this diagnosis of him being 'barely on the spectrum' was somewhat relieving. Because I saw that… I saw that Panayiotis was responding to so many things. Namely, he was smiling, umm … the child didn't exhibit the characteristics of severe autism that I knew about. (…) So hearing that he was 'barely on the spectrum' was relieving to me.
(…)
X. At … at first there was uncertainty. Because, okay, I knew he was on the spectrum … he is on the spectrum … barely – this is the keyword. We went to see a developmental specialist who saw him umm … and I remember that he drew a line on a piece of paper and told me, "if this is the spectrum, and this is where severe autism is, and this is where neurotypical children are, your child is", he drew a circle in the middle of the line, "he is around here, so he is within the healthy side too".
ED. Ah okay.
X. That's what the developmental specialist said. So I hold on to that, umm because that's what kept me going that 'okay, this will go well, the condition is good, let's say'.
Xenia, mother of a 7-year-old child diagnosed with autism

Xenia focuses only on specific parts of her child's diagnosis, that he is borderline in the autistic spectrum and he is also on the healthy side, which functioned as a great relief for her. Other parents choose to include the child's difficulties in a more general context, such as Marina who presents autism as a more general category of neurological disorders (*M. … they then told us that this is called autism, because autism now is a spectrum, an umbrella term that encompasses every case. So, every neurological case*). Other parents distinguish between autism and autistic traits, choosing the second as a more painless description (*A. He told me that … that he is on the spectrum, I understood that he is not really autistic, it's just … He exhibits some characteristics. And he told me that if I carry on with the therapies, he would get better, he would improve, and no one would ever notice anything*). Parents seem to present their child's diagnosis, actually select a diagnosis' description, in a way that comforts them and helps them handle it more effectively emotionally for themselves but also within the social context. The social dimensions of the diagnosis are discussed in chapter 5.3.

Other parents emphasize on (v) *the appropriate support* to achieve acceptance, *state or professional* support. Most parents highlight this support as something that would have helped them, not as something that they already benefited from. The mother in the following extract explains the kind of desired provision that would allow her to feel safe:

ED. Umm … do you think there is anything that would help you accept it?
(…)
E. Look, I would feel more relief if I knew that there's really a vision in Cyprus, something that would help these individuals. That, okay, she has this issue, I won't always be able to be with her, she won't be self-sufficient, but even if she had to go elsewhere, it would be as if she was still with me.
ED. Yes.
E. That they would treat her like I do.
ED. Feeling calm that she can go somewhere else.
E. Yes. I'd feel more relief and I would be more … yes, to accept that it's alright.
ED. Okay.
E. I would think that she might have been, she might have been another woman that never had a child, that never got married. These women exist … Okay, Sophia won't be capable of working but … she will … she might be able to live as normal as possible, with the right infrastructure and suitable … with people who would …
ED. I understand. Who would be able to take care of her.
E. Take care of her, exactly this. It would be easier to accept it. It's, it's okay. She has this problem; she could have had another one …
Eleftheria, mother of an 11-year-old child diagnosed with autism

Eleftheria describes how with the appropriate state support she could feel more relieved for her daughter's future and accept her disability as a problem among others. The mother focuses on the social context, where the disability derives from, and not on the child's dysfunctions. This narrative is very close to the social model of disability (discussed in chapter 4.1.1.), where the child's inclusion into society and the experience of as 'normal' a life as possible do not depend on her progress but on the appropriate adjustments available to her.

Another interesting point of this narrative is how the mother represents this state support, provided by a single woman who wants a child. The mother's scenario links two, undesirable for her, statuses and two parallel compromises: a single woman who does not 'deserve' to have a functioning child and a child with disability who does not 'deserve' proper care. Thus, the mother's vision for her child's future includes integration in the community but, at the same time, not equality towards the child, not to be unconditionally cared unless out of necessity. The woman's representation as carer is dominant in this narrative and possibly underlies the mother's reasoning.

The required professional support is something that is also raised by other parents. The mother in the following narrative exemplifies the significance of this support, but in a different perspective:

E. I mean that when you announce that to a parent, they are either prepared for something or they're not, when you announce it, when you're a doctor and you announce a child's issue to a parent, besides having to announce it … elegantly. You also have to look at the parent and say "don't worry" to them.
ED. That this is it.
E. This is it, on one hand. But … there are ways … To, take your baby to do those therapies … don't worry!
ED. To reassure them somehow.
E. Yes. In any way … A parent can't be reassured though. (…) This is a huge chapter. I believe that, I don't know … the doctors are dehumanized? I don't understand.
(…)
E. I would have preferred the doctor saying, "look. Your child exhibits these autistic characteristics. It's not the end of the world. There are therapies that your child can do that will be of benefit. You can visit this organization and ask for more information". The ideal for me would be, umm in a different world, of course, when they announce anything to the parent, because they announce other things beside the autism diagnosis that … A psychologist should be there. A psychologist should be there to hold your hand. And tell you, "don't worry". And instead of having the next appointment after half an hour, make it after one hour. Or when you get out of there, the doctor should accompany you to meet a psychologist, meet a psychologist in a different room.
ED. Mmm.
E. And tell you, "take a deep breath, cry (emphasized)! And this is what we will do now". "You can go here", provide you with information, where to go, there's this institution. (…) Instead of just leaving the doctor's office and thinking, "okay. What do I do now?
Evangelia, mother of a 6-year-old child diagnosed with autism

Evangelia discusses the necessity of professional support in a structured way. In fact, the mother explains that ideally the announcement of the diagnosis should be accompanied by the presence of a professional counsellor or psychologist, who will help the parents understand the diagnosis and feel secure at the beginning of this difficult for them experience. This extract also reflects, in the most obvious way (*The ideal for me would be, umm in a different world, of course*), the organizational and structural lack of relevant support services in Cyprus, as well as the gap in the provided care path for parents of children with developmental disabilities (further discussed in chapter 1.6.2).

Other parents (discussion group) discuss about the role of the professionals to the announcement of the diagnosis, with their input being, apart from the emotional support towards the parents, the profound understanding of the diagnosis as well: "*… when the doctor announces it, they should also explain it. Not only the child's condition and its name. What the disease's title means (…) I have a master's degree in umm medical genetics (…) I have studied Down syndrome. If you tell me what Down syndrome is, I may be able to give you the biological perspective. (…) So? So what? What will …? What does that mean for your daily life? What does it mean for you as a mum, and what does it also mean for the child, how can you, as a parent, help your own child. That's why, the support, umm … should be for the future as well, to help you accept it. It's support after the acceptance, but also support for (emphasized) the acceptance".* The mother analyses how the appropriate approach of a professional can contribute to the parents' acceptance of the child's diagnosis.

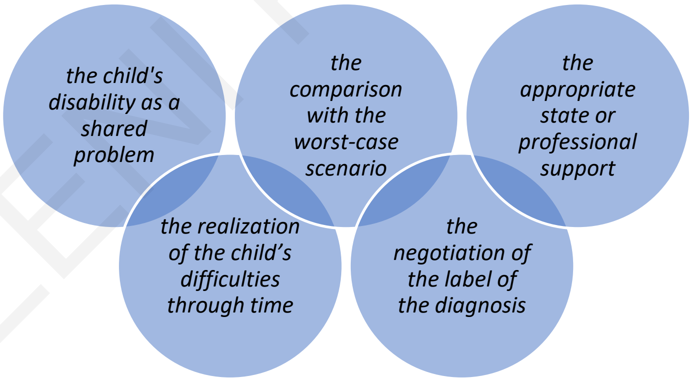

Figure 5.IV. What helps parents' acceptance of the diagnosis

5.1.5. Summary

The parents focus on the process of the diagnosis as an important starting point from which they familiarize with their children's disability. The *announcement of the diagnosis* differs from case to case, as does the way this announcement affects the parents. Some parents appreciated the assertive way, in most cases though the child's diagnosis is presented as something tragic while there is no particular structure to this announcement. Professionals often adopt a position of power, which leads parents to feel further anger and frustration.

The shock is the *parents' first reaction* to the announcement of the diagnosis, whereas many parents represent the diagnosis announcement as a symbolic loss of their child. Most parents knew nothing about their children's diagnosis beforehand and many of them report that they needed time to understand the diagnosis. As to their *long-term reaction*, parents report acceptance, not acceptance and distancing from their child's diagnosis. The acceptance of the diagnosis is approached, though, in several ways by the parents: as an acceptance with no choice, as competitive to the effort and as a process of acceptance.

This chapter also discusses what *helps parents' acceptance* of the diagnosis. Representing the diagnosis as a shared problem, realizing the child's difficulties through time but also comparing it with the worse-case scenario often help parents process their child's diagnosis. Additionally, the negotiation of the label of the diagnosis and the appropriate state or professional support seems to enhance the parents' acceptance of the diagnosis.

5.2. Parents' interpretation of the diagnosis

An interesting enquiry that concerns parents is how they interpret and understand their children's autism or intellectual disability. The parents' narratives contained an important part about what they think is the reason of their children's disability. Interestingly, parents' interpretations were different, but there were some common themes as well, which I discuss in this chapter.

5.2.1. As a random event

Some parents presented their child's disability as a random event, as this father does, while discussing his opinion about the various support events for people with disabilities:

L. Exactly! Because, God forbid, maybe it's your child that has it, or mine. It happened to me, I'll take it.
ED. Well, yes.
L. If it happened to you, it would be you.
ED. No one has signed a contract about it.
L. Exactly! You don't know what will happen. That's why, just like you have to accept that my own child will have to live decently, fairly, umm receive all the care they deserve in order to live a satisfying life until their death, why isn't my child entitled to this, and has to beg to claim this. (…) If it was you, would I say, "no, why should that person have this? Why should they be entitled to receive money?" Why would I say such a thing?

Loucas, father of a 7-year-old child diagnosed with autism

Lucas interprets his child's autism as a random event. Talking about the benefits and the necessary services, he likens disability to a lottery, which can "happen" to anyone. The father was the one who "got" the lottery this time, but it could have been the interviewer or anyone else. No one can determine the random event of a person's disability. Another interesting point of the father's narrative, is the question of the certainty of non-disability. No one knows if a disability will come in the future, for him or his family (*You don't know what will happen*). Non-disability is not a given fixed status but a random variable that can vary from one moment to the next.

The child's disability as a random event is often mentioned by parents. Let's take the following extract as an example:

ED. Umm you feel like it's … like … it's like explaining something.
A. Yes. I don't want to explain it. What happened, happened.
ED. Okay.
A. We move on.

Anastasia (group discussion)

Anastasia refers to her son's autism as a random event that happened, from where she needs to move on. Similarly, Evangelia, another mother of the same group discussion comprehends her child's autism as something "that happened" to her life, which she will deal with (*I said this happened to me in my life, I will deal with it*). It is obvious that some parents refer to their children's disability as a random event, without further analysis or interpretation. It happened and let's move on. This might also be an effort to normalize the experience of disability as another life experience, without searching the underlying reason or the source of disability. This is very similar to the approach of their experience as a 'no-different' parenting experience, analyzed in chapter 6.1.4.

This consideration of the randomness of disability is, yet, a recurring pattern in the parents' stories. The mother in the following excerpt exemplifies this interpretation:

M. It's nonsense! If it's meant to happen, it will happen. Since umm… I met women who said that it happens because of age, and other nonsense. There's been many women who gave birth when they were 20 (…) Not 40 like I was, for example. (…) Okay, it's something that goes amiss at conception, something you can't see. Normally you shouldn't, you can't say "it's your fault", or "it's not your fault". No one wants this to happen (…) It's something that was meant to happen, it happened.
ED. Well, okay, aside from the scientific explanation (…) umm how do you explain it? (…)
M. You simply accept it. It's not, it's not, how can you explain it?
ED. You don't … You think that there's no explanation.
M. No. (…) No one wants to give birth to a baby that has any kind of disability. It happened! If you're currently fine, for example, but you crash your car and you become disabled, should they kick you or kill you? That is the same thing.

Maria, mother of a 6-year-old child diagnosed with Down syndrome

Maria intentionally abstains from any interpretation because she feels that her child's diagnosis is fatal, is a random event that can happen to anybody. Focusing on the societal reactions around parents of children with disabilities, which she disapproves, and using fervor wording (*It's nonsense!*), the mother explicitly rejects the need to explain the disability and thus the possibility of attributing fault to anybody. Additionally, by presenting the developmental disabilities as similar to the disability resulting from a car accident disavows the responsibility of the parents and emphasizes on the randomness of her son's syndrome and of any other diagnosis.

5.2.2. As the parent’s responsibility

On the contrary to the previous theme, other parents argue that there is a part of responsibility that burdens the parent. The father in the following extract exemplifies this consideration:

M. Not really. Not really. Okay, I’ve thought about it, but I haven't researched it. I haven't researched it to see whether it’s hereditary, in order to interpret it. And either way, that thought really doesn't help me. I don’t feel like the thought of learning about … would help me, what I told you earlier, for example, when my mother asks, “how does this happen?” Thinking about it doesn't help me.
ED. Hmm, hmm.
M. Sometimes I feel guilty, because it’s true, especially in the past, it’s true that … if for example … (unintelligible) if there is a hereditary aspect, it means that he got it from me. Okay? Because I had some similar characteristics. Good? Umm but it doesn’t, thinking about it doesn’t help me. And I don't think about it. Okay, I can’t, I can't interpret it. I’m not, saying I didn’t do any research about it, I didn't search if … (unintelligible) and to what degree. But that’s not the most important thing, it’s – that’s my way of thinking in general – I always think “will this help me solve the issue?”
ED. Mmm.
M. I feel like it won’t help me … it certainly won’t solve the issue.
ED. Hmm.
M. Would I feel better if I know? I am not really convinced.
Marcos, father of a 7-year-old child diagnosed with autism

The father examines his responsibility from the perspective of heredity, arguing that the responsibility probably weighs on him, as he finds some common traits of himself and his son with autism. However, this reasoning is not useful to him, to understand or to find a solution to the problem. It is interesting, though, that the father does not firmly reject his possible responsibility, while he admits feeling remorse in the past for it. This feeling of remorse consists an indirect acceptance of his responsibility due to inheritance. This sense of responsibility may add extra burden to the father in raising a child with disability, extra burden for the child and the parents themselves.

Some parents reflect on their responsibility, but because of decisions they made related to medical reasons. The mother in the following narrative focuses on her vaccination:

E. Yes, I think it happened because of the vaccine that I got when I was nine months pregnant. I was pressured into getting it back then, when the bird flu struck, we were bombarded about it non-stop … on TV. I remember going to get the vaccine, but eventually not getting it and leaving. My daughter, who was 13 years old, told me, "mum, what if you get sick or if another kid gives me the disease at school, and something also happens to you", and so on. Umm some doctors back then supported getting vaccinated. Umm I had seen a pregnant woman in Makarios Hospital who told me, "my doctor from America told me to get the vaccine". And I don't know, I think that … I feel guilty that the vaccine may have played a part. Namely, I believe that there was predisp… the predisposition was there, and the vaccine made it worse.

Eleftheria, mother of an 11-year-old child diagnosed with autism

The mother brings the interpretation that the vaccine was a triggering factor, believing that the child had a certain predisposition and the vaccine "awakened" this predisposition. Since the responsibility for the decision of vaccination was hers, already since then, she considers herself responsible for her daughter's manifestation of autism.

Other parents focus on their responsibility due to decisions they made related to other medical reasons. Demetris, Eleftheria's husband, attributes the explanation to their wrong family planning and specifically to the fact that they had their second child 12 years after their first one (*Our family planning was poor*). Andriana, mother of an 8-year-old son with Down syndrome, discusses about her age when she gave birth (*That it's because of age … That it's your fault for leaving it at such a late stage, for example*) and the responsibilities that this reasonable explanation of science places upon her. Irene, in the following extract, argues about her guilt relating her child's disability to her late intake into the hospital. All these health factors that influence the manifestation or the incidence of the child's disability emphasize on the significance of the parents' decisions, which are considered critical in retrospect, leading to the parents' indirect responsibility regarding their child's disability.

Some parents discuss about their own responsibility but at the same time they highlight a religious underpinning factor. The mother in the following extract talks about parents' sins payed by the child:

I. Whenever I see kids with severe disabilities, for example. Okay? Um the first thing that comes to mind is, "what kind of sins have these parents committed for a child like this to have been born?" That's what I always say. I don't know, that's what comes to mind. I feel sorry for that child, and I think to myself, umm, "how is that child to blame?", "what kind of sins have the parents committed?" That's what I say, Eleni.
ED. Hmm. Umm have you, for example, found out what your own sin was?
I. Umm when me and Elias got married (…) he told me, "my mum will live with us". (…) but I didn't get along with my mother-in-law. (…) And I thought that maybe I was nervous, that I was stressed, what if I could have been calm? (…) Would Nayia have been born as a normal child? And I feel like it's my fault. It's my fault that she was born like this, okay?
ED. Okay. You have umm …
I. But I always think that … that it's my fault. If only I could make Nayia be born normal. … Umm I don't know, that may be wrong. My friend Maria tells me, for example, "umm it just happened, it's not your fault" (…) That's how she happened to be born, but inside of me umm … this suffocates me. That it's my fault.
ED. Umm nowadays, after being on this journey, what would you have done differently, Irene? (…)
I. For her to not have been born like ... I wish Nayia was born normal. Hehe (laughs).
ED. I mean, if it was up to you.
I. That day, for example, when the … they weren't playing, they were like this (points with her hand at her belly). And If I had gone to Makarios sooner. Okay? I would change that. But I hadn't realized. (…) That day, let's say, the babies weren't playing, they weren't moving inside. And we went to meet our friends for coffee in Ayios Dometios. With Elias. That's when one of the babies got detached from the placenta. Umm … the bleeding started. We came to Makarios, by the time they could see me, by the time they could take me to the surgery room, what happened? Her brain wasn't receiving oxygen. Let's say, if I would've gone to Makarios sooner. But …

Irene, mother of an 11-year-old child diagnosed with cerebral palsy

In her story, Irene represents the disability of every child as the fault of the parent, by emphasizing a religious perspective: the parents committed some sin for which the children with disabilities are paying. In her own case, she evaluates the stress she experienced when she was pregnant as a possible factor. The interesting point here is that she doesn't firmly believe this, it's just a possibility, yet she has a very deep-rooted guilt. Her responsibility seems to make her wonder how she could have managed to have her daughter born normal. In her attempt to explain it, the mother mentions details from the day of delivery and the time of her arrival at the hospital, which she would clearly change. The mother's guilt appears to be more related to her late arrival at the hospital, as evidenced by the confidence with which she discusses the matter.

The mother's narrative has a strong separation of the normal and the non-normal. Particularly for Irene, mother of twins, one of whom with cerebral palsy, this is more evident as she talks openly about the normal and the non-normal child. The normal represents the desired and the expected (*For her to not have been born like ... I wish Nayia was born normal*), which didn't finally happen, according to her probably because of her own fault.

The mother in the previous as in the following excerpt, talking about their responsibility, make clear references to the religious aspect. Theodora in the next narrative considers that God sent her son's developmental disability but due to her own fault:

T. Eleni, the reason I still, the reason I still say, "why did this bad thing happen to me?" (…) Because, in my own mind, I think that I have done my duty, heh (smiles), and I have paid my dues because of my brother. And I think to myself, why would God send this my way, now.
ED. Ah I understand. Yes. So, do you view it as a punishment somewhat? That it's, let's say…
T. Yes, yes. Yes, that's how I view it. (...) And I was angry with God. (…) And I know that God does not punish. But I was still angry. And … umm … I asked "why would you send this my way?" But I'm sure umm that like with other things in my life, umm … I will, I will understand the reason. That he has sent this my way. I already do.
ED. So what is the reason? What do you believe? Why has he sent him to you?
T. Umm … to make me become more mature, to get over the complexes I felt about my brother, to fight. Because I haven't gotten over them. And now with Petros, I will come, I will be forced, because he is my child, umm to fight, so I will have to, maybe I didn't learn the lessons I should have learned, not to play down it. So, I haven't … learned umm … what I maybe should have learned.

Theodora, mother of a 6-year-old child diagnosed with autism

The mother considers herself to have paid her "debt" because of her brother[18]. Again here, as in the previous narrative, the idea of "what sins am I paying" returns, since the presence of a person with disability in the family, either a sibling or a child, is represented as punishment from God. Overall, the mother interprets her experience as an assessment that

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[18] Theodora's brother is an adult with disability (congenital disorder).

God has put her through, which is for her benefit, in order to overcome her inferiority complexes, for her personal growth through the acceptance of her child. Although the mother rejects the version that God is a punisher, she nevertheless uses punitive terminology. In conclusion, the mother's interpretation about her child's autism sums up to a test of God for herself with the purpose of her personal development and empowerment.

This extract illustrates the representation of disability as a disadvantage, as an undesirable condition that causes shame. The mother clearly discusses about an inferiority complex, a secondary stigma (discussed in chapter 2.2.3.3), which she "struggles" to fight from an early age because of her brother’s disability and has to fight more to overcome because of her son’s autism.

In all these narratives, parents express remorse, which signals their responsibility regarding their children’s disability: parents could have done something – even theoretically but also practically – to prevent their children's disability. And not having done it means that they hold responsibility and they rightfully have regrets. Even though parents don't say "yes, it's my fault", they openly express their concern about whether they themselves have, to some extent, contributed to their child's disability. Besides, they conclude that they have contributed through heredity or through their decisions, like vaccination, reproductive age or late examination.

5.2.3. Interpretation related to God or other superior power

Other parents interpret their child's disability as purely God's will. The following group discussion is quite demonstrative of this theme:

ED. (addressing E.) E., from what … what do you think helps you stand on your own two feet?
E. I believe that there is an invisible hand. God’s? I don’t know whose hand it is. And is sending to us. It sends this your way, “today, you will have these issues to face, stand on your own two feet, fight it …”
M. “And I will help you too”.
E. Yes. “I’m here”, for example, and he sends your way everything that you can handle for one day. Not more. All you can handle for one day.

Evangelia & Marina (group discussion)

The mothers in this discussion group agree on the interpretation that the child's disability is sent by God or by another superior power. However, there is a clear targeting, as if this was planned and according to the capabilities of each person. The interesting thing here is that this interpretation inspires a sense of security in mothers (*"I'm here"*). God's will here does not work punitively, but empowering even complementary. As mentioned by Theodora in the previous theme, here again disability is interpreted as sent by God or some other superior power, but for some reason. According to the mothers of this group, the reason lies in the empowerment, the struggle and, perhaps, the assessment of the parents.

Similarly, Alexandros reflects on his experience of raising his 6-year-old son with autism as another test of God towards him:

A. I've been through hard times. (…) So, what happened with Philippos, it's just another storm, like the previous ones I went through. (…) Because, maybe ever since I was born, I'm being tested. Am I the only one? No. Everyone has their own cross to bear. (…) But whatever I had to endure in this life, I didn't drown. And what brought us Philippos, and every Philippos, whether you call it life, God, or anything else, the universe – that is what also brought us Artemis later on – do not (short pause) do not affect me that much, I don't feel like I'm 'drowning'.
ED. You have been tested. You have …
A. It feels like another weight has been added on your back while you're trying to swim. And you're trying to stay on the surface. Every, every issue, every, let's say, umm … it's not, you can't call it a problem, it's … what life brings you, it brings challenges your way. You see? So, every … with everything coming your way, it's all about whether you will be able to cope.
ED. Mmm.

A. Or to adapt. I have learned how to adapt. (…) There have been many changes, many changes from a young age. So, I learned how to cope with changes (…) So, that may have tamed me (…) So … I don't, I can't say that, "you know what, oh my God, I'm drowning, I don't know how to deal with this …".

Alexandros, father of a 6-year-old child diagnosed with autism

The father in this excerpt, talking about his traumatic experiences as a child, presents his child's autism as yet another test, another challenge to face. Although throughout his narrative he uses religious terminology, he does not clearly adopt a deeply religious position at first. He prefers to talk about a superior power, which he hesitates to name – God, universe, life – and which, according to him, sends these challenges. The challenges include trials, namely his son with autism, as well as rewards, namely his other child. Here as well, there is a sharp separation between desirable and undesirable, where the disability of the one child is clearly identified as undesirable.

The father's argument includes strong elements of effort, struggle and patience, which are central concepts in several religious narratives. Additionally, the pattern of not giving up returns here: no matter how hard experiences he went through, no matter how much this superior power tested him, he survived. According to him, it is a matter of adaptation and coping, since challenges will always be sent. Concerning his coping skills, the father expresses an intense confidence of managing those challenges. His confidence is a result of the trials he has gone through, which in a sense have toughened him. Thus, the trials of the superior power are meant to strengthen and empower the father.

Many parents do not name directly God, but talk about some other superior power, as the mothers in the discussion group and Alexandros. On the contrary, Nicolas in the next extract, clearly speaks about God:

N. Umm but whether it's God who brought this, yes. That's how I view it. Well, if God brought this upon us, if he brought this upon us as punishment about something … I believe that it has not really happened this way, because there are worse people, umm criminals and others, who have a good life, making good money and so on … their whole life is fine. I don't think God brought this as punishment. God may have sent this my way to rehabilitate me, or to correct me. That's what I believe.
ED. To test you, would you say?
N. (takes a deep breath) This again, to test me, about what? I was a simple person, who umm believed in God. I didn't do anything criminal or something out of the ordinary for God to test me in some way.
ED. Mmm. Hmm.
N. And … that doesn't mean that if someone is a criminal, they should have a child like this or that something should happen to them. I just think that the child was sent by mistake … Hehe (smiles) (…) Umm I'm also trying to understand, because everyone has made mistakes in life, and maybe I've done something that may be considered serious in God's eyes, and in order to rehabilitate me, he has brought me this. But on the other hand, I still think 'but there's people who have done worse things than I have' …

Nicolas, father of a 5-year-old child diagnosed with congenital brain disorder

The father is brainstorming on the reason why God send him his daughter's disability. He does not negotiate the existence of God but he can't understand why this experience was sent to him. He rejects the idea of punishment, as he considers that he has not committed any serious fault. He is closer to the interpretation that it was sent by God to make him wise, to correct him. Thus, the intervention of God is here, as well, but for some corrective reason towards the father, in order to become a better person. Of course, he also leaves open the possibility that the disability was mistakenly sent to him by God. Similar to the group discussion, the search for the interpretation does not torment the parents, they do not anxiously search for the explanation, as they seem to feel safety and trust in the wills of God: God sent it for some reason and that is enough.

Although rejecting it, there is a hypothetical possibility that the child's disability is sent as a punishment. Thus, disability is an adverse life experience, an undesirable condition sent by God to punish. It deprives the parent of the opportunity to have a good, normal and desirable parenting experience. Once more, the sharp separation of normal and non-normal is obvious in the father's narrative. In this story, however, the separation between good and bad is also evident in good and bad people, in good and bad actions, in people with right and wrong choices (*there's people who have done worse things*). The theoretical separation of the father into normal and non-normal fits into a wider context of "right" and "wrong", where disability is included in the "wrong" category.

In total, the discussion of God was interspersed in several parents' narratives, even when they did not reflect on their interpretation of the child's disability. For instance, Ioanna was frequently referring to her child's disability as happening because of God (*It comes from God).* Marina, throughout her interview, expressed her religious prayers for several reasons (*Praise God! Everything comes from God, Eleni*).

Apart from the parents' interpretation relating to the diagnosis, the religious faith was, additionally, reported as a significant resource for parents, represented as a support or resulting in the strengthening but also to the loss of their faith because of the child's disability (further analyzed in chapter 6.3.2.). Besides, it is obvious that religious belief is widespread, well established and deeply rooted in the parents' accounts. It is a common aspect mentioned by parents and highlights the social context in which the interviews took place.

5.2.4. Interpretation related to medical factors

Some parents interpret their child's disability in purely medical terms, referring to different factors such as heredity, negligence or even the association of autism with vaccination. Ioanna in the following extract considers her child's disability due to medical negligence:

I. Umm this happened to us because of the doctor. Umm negligence. (…) Who didn't take a proper look at our medical history, he didn't give us any shots, um … I needed to take blood pressure pills I wasn't taking before … back when my blood pressure was high … so many things came from the doctor (…) These are the things we live with today. It comes from God too, but I believe that the doctor plays a bigger role. Negligence.
ED. You also spoke about God, that maybe it was God's will?
(…)
I. I think that it's because there are a lot of children like this … is it God? I don't know.
ED. Hmm.
I. I think this is because of the doctor, more than it is because of God.
Ioanna, mother of a 7-year-old child diagnosed with cerebral palsy

The mother believes that a series of explicit medical mistakes resulted in her child's disability. It is interesting that the mother uses the first plural in her words (*our medical history; didn't give us any shots*), referring to what happened to them, as disability is something that happens to the child and the family. As quite a religious person, she also considers the possibility of her child's disability as the will of God. Although she wonders, the prevailing interpretation for her is medical negligence.

In the next narrative, the father seems more confident about the medical interpretation of his child's disability, although he had initially taken various actions of a religious nature:

Y. No. We are pretty realistic and we see what we see. It doesn't … umm it has nothing to do with what we think, what we believe, or … It's, it's clearly medical (…) The treatment is medical too, there is no … some reason, let's say, to either … to … Even what we have done with churches etc, for example … it's not … it's clearly a medical issue.
Yiannis, father of a 4-year-old child diagnosed with nodular sclerosis

Yiannis, discussing his interpretation about his daughter's disability, focuses on the medical aspect, explaining that it is a purely medical issue. Despite having experimented with various religious activities at first, such as visiting churches or monasteries, these actions were finally not accompanied by any meaning and were invalidated in his account. It seems like him and his wife were somehow influenced by the broader family's understanding of the issue than were looking for an answer with this religious activity. Adopting a "realist" approach, he strictly remains to the medical interpretation of his child's disability.

In these two last extracts, even if there are some dilemmas, the view of science ultimately prevails. Parents are facing some doubts, they wonder or try different things but they end up with confidence and security in the medical view of science. Another interpretation related to medical factors is heredity, which was mentioned by some parents (*A. I think it's a matter, because I have diagnosed a person in the family, I think it's a matter of genes. (…) I consider it a fact*). This is another interpretation characterized by the certainty of parents supporting it.

However, there are other medical interpretations that are related to more controversial factors, like the quality of nutrition nowadays, the vaccination, etc. The father in the following extract exemplifies this idea:

V. Umm … I looked into vaccines, because we had an issue … (sighs) … A few months back, we had Anna vaccinated (…) we had her vaccinated but I had some doubts. Not about the vaccine. Umm I read that the vaccine is for babies aged two years old and older … and we had Anna vaccinated when she was one and a half years old. (…) I can't, I can't talk about something I don't know. Not even if … umm if there was something or that … I looked into it (unintelligible) (…) Yes. I looked into it, in a way … You can't figure it out. In any aspect. Everything I'm telling you is not proven. But there are a lot of similarities (emphasized) to the autism spectrum that I think are related to the vaccine.
ED. Mmm. Mmm, mmm.
V. Maybe it doesn't have to do with the specific vaccine. Let me give you an example. A baby is taken to get a vaccine. Five ml. One baby weighs two kilos, and the other weighs seven kilos. They are the same age. Well, is that normal? (…)
ED. Mmm. Mmm, hmm.
V. Could she have, could Anna or any other baby … be more susceptible to something? And that by getting a vaccine, which is a reaction to the organism, it caused (…) it caused a change in the baby's organism, it may have caused or changed something, in addition to

the part which was sensitive. And it was created. So, it may not have been the vaccine itself that causes something to the children. But in a different way, because of some other factor … It may have caused a different reaction in the baby's organism … in that specific part.

Vasilis, father of a 6-year-old child diagnosed with autism

Vasilis, in an earlier part of the interview, presents himself opposing to the modern medicine, questioning the current medical views and presenting them as confusing or unjustified. According to him, there is a strong association between autism and vaccination, which works as a trigger: the child has a predisposition and the vaccine as a shock-reaction in combination with other factors results in the autism manifestation. This is similar to Eleftheria's consideration (chapter 5.2.2). Unlike her, though, Vasilis does not take any responsibility but he discusses the possibilities of the vaccine contribution to his daughter's autism.

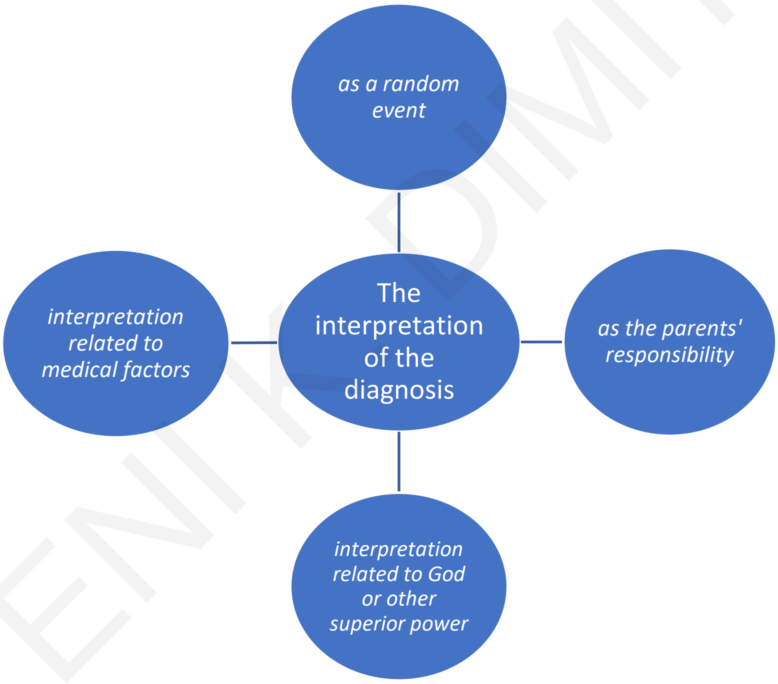

Figure 5.V. The parents' interpretation of the diagnosis

5.2.5. Summary

This subchapter examines parents' understanding about their children's diagnosis. Although the parents' interpretation is not identical, four main themes stand out. Some parents approach their child's diagnosis *as a random event* that can happen to anyone.

Other parents focus on *their own responsibility*, acknowledging their guilty feelings about their child's diagnosis. The *religious element* is strong for some other parents, who attribute their child's diagnosis to a superior divine power, namely God. Finally, there are some parents who adopt a more realistic view, considering that the interpretation of their child's disability can only be *related to purely medical factors*.

5.3. The social dimensions of the diagnosis

The child's diagnosis is, among other things, a very critical issue that affects the whole family. Some parents represent the experience of the child's disability as a strictly family issue, which others cannot fully comprehend neither realize what it means, unless they have something similar in their family (*A. I still say it, unfortunately. "We have an issue in our home"; I. I think they don't understand … If you don't experience it in your own home, you don't know how it is*). This perspective of the child's disability as a family problem, indicates the social dimensions of the child's disability.

Parents are asked to place their child's diagnosis in the social context and represent it not only as a personal but as a social issue as well. This chapter attempts to describe exactly this social dimension of the parent's experience, namely *the kind of dynamics developed with the different others*. Four thematic sections emerged by the parents' narratives regarding the social implications of their child's diagnosis: (i) *misunderstanding and conflict*, (ii) *loneliness and distance*, (iii) *support and connection*, and finally (iv) *stigma*.

5.3.1. Misunderstanding and conflict

The kind of dynamics developed with the different others reflecting the social implications of their children's diagnosis are summarized in 3 main patterns. Firstly, there are *different considerations* but also different reactions concerning the diagnosis between the two parents of a child with disability. Further, the child's diagnosis affects the parents' relationship, provoking some *conflict*. Additionally, the extended family *does not really understand or deny* the child's diagnosis, which makes parents feel angry or hurt.

The representation of the child's disability within the close family can vary, depending on the understanding of each parent but also on their emotional reaction to the child's diagnosis. The mother in the following extract discusses this different perspective between her and her husband:

D. Yes, first of all, things were dysfunctional between me and my, and my husband. Umm pfft … there was no harmony … umm there was no support towards one another. We didn't have the same perception of the situation. Umm that's what lead to … each of us doing different things. One of us was feeling worried, was concerned about a lot of things, and the other one not even realizing that these issues existed. (…) Yes, I still think that he still hasn't realized … how much effort and the time it will take for our child to achieve something that may be very easy for another child.
ED. Mhm, mmm. Okay. And how did this difference in perception affect you?
D. Umm … it caused me even more stress, it made me sad, it made me feel an unbearable loneliness. Well, it's the stress of responsibility, the fact that I make decisions on my own, there is no one else who would think about it with me, and discuss a variety of issues with me. I mean, to contribute (emphasized), to also be a part of the … process.
Demetra, mother of a 6-year-old child diagnosed with Alpha syndrome[19]

Demetra describes how differently she and the child's father comprehend her diagnosis with a rare syndrome. Along the way, it became apparent to her that the two parents have a completely different perception of the child's situation, which led them to act differently and made her feel the burden of responsibility but also loneliness throughout the "struggle" of supporting the child. Other parents, as well, focus on the diagnosis' understanding, with the other parent not having fully comprehend the diagnosis and its consequences, even projecting a sense of relief (*T. … I also thought that my husband didn't understand at first. I can say that I felt it more, I believe that I thought the issue is more severe than my husband did*).

Some parents describe the parental reactions about the child with developmental disability as unequal, with the one parent taking more of the responsibility as well as the load of the child with disability. The mother in the following narrative exemplifies this different reaction:

E. I felt lost but (emphasized) I had to stand on my own two feet, because the father, my husband, was … like a zombie, he was walking around, and you didn't know …

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[19] Alpha syndrome is a pseudonym of a rare syndrome.

ED. Hehe.
E. Can he walk? Is he alive? Is he okay? And I also had to stand on my own two feet as a mother (emphasized) and say, make choices I never had to make in my entire life, and that had to do with my baby.

Evangelia, mother of a 6-year-old child diagnosed with autism

The mother emphasizes the different reactions between her and her husband to their child's diagnosis, as a result of which she was required to undertake sole responsibility and action for the child. Other parents report the same difference (*N. Basically, my wife went through a hard period, she was crying, on the verge of depression*). Interestingly, for some parents it is important to emphasize that the other parent was more affected by the child's diagnosis, for example mothers who discuss how they were forced to take responsibility themselves (*E. I just umm got in charge, I got in charge and moved forward*) while fathers discuss how mothers overreacted emotionally (*A. … A. took it to heart. The word 'autism' or 'Asperger' crushed A. (…) A. was panicking. She was … umm she got mentally overwhelmed, and she would cry when overwhelmed with emotions*). The main argument is that for the other person it is more difficult to deal with the condition. This seems to empower somehow the interviewed parent, giving a sense that they are in control of their reactions as opposed to the other parent or that they are able to take responsibility.

An interesting point raised by some parents is how the child's diagnosis affected the parents' relationship. The mother in the next narrative explains this effect:

ED. After you received the diagnosis (…) was your family life affected (…)?
X. Yes, my relationship with Loucas was greatly affected. Umm … we argued more, in the sense that we would disagree about how to handle our child.
ED. Ah.
X. And we still disagree. Loucas, for example, wanted to be more flexible and conciliatory towards him because of his issue. Umm I believed that we should behave umm … normally towards him. You get it.
ED. Like you would do towards any other child.
X. Yes, yes. Umm and I still believe that. Of course, while still being understanding about some specific characteristics that he may have, for example, and characteristics that cause difficulties because of his issue. So yes, we had different issues and arguments at home … umm … yes, there was some frustration.

Xenia, mother of a 7-year-old child diagnosed with autism

The mother describes the conflict that arose between her and her husband. The way to treat the child became a disagreement cause, which relates directly to how each parent understands and reacts to the child’s diagnosis. The disagreement is confirmed by the father as well, in his own interview (*L. Because she doesn’t want to hear anything bad, she doesn't want to think of it.* It upsets her (…) *And we disagree (…) we have this peculiarity, I am straightforward, my wife is the exact opposite, um we clash with each other a lot, it’s getting worse (…) Ever since then, she would tell me “you’re exaggerating and … leave the child alone, to grow up”*).

As to the extended family, the parents believe that they do *not really understand* or *deny the child’s diagnosis*, which makes them feel angry or hurt. The father in the following narrative explains this lack of understanding:

ED. Mhm, mhm … do you remember having a conversation with anyone close to you?
(…)
D. Yes, once, with my father. He had some plants in his yard, and the cacti grabbed Sophia’s attention, so she cut one off. Hehe (chuckle). And he started yelling at her. I told him, “dad, you know that Sophia has an issue”.
ED. Yes.
D. *“She did it because they grabbed her attention and she wanted to cut one off”. Well! When she cut off a second one, he told me “get ahold of her, she is spoiled. That’s why she is doing this”. “Okay”, I told him. “Come on, let’s go because we have places to go, we have another appointment”. So, I didn’t say anything to him. We picked our stuff up and left.*

Demetris, father of an 11-year-old child diagnosed with autism

Demetris reports his father’s difficulty of understanding the child’s presenting issues when he was confronted with them. The father felt that the child's behaviours were generally characterized as spoiled, indirectly indicating a questioning of the diagnosis, which puts the father in a difficult position.

Often, some parents are hesitant to tell their own parents about the child's diagnosis precisely because of this lack of understanding. Elena, mother of a 10-year-old child with autism, explains this reasoning:

E. Umm the family, umm Lambros' parents, (…) even though we told them about it, we tried not to mention the sever … not to show them the severity. Well, you know, it was the typical "no, it will go well, the baby will speak, the cousin of that aunt's cousin also took long to be able to speak and…" Umm it took a lot of work because, especially because my mother-in-law is more sensitive, we had to explain to her that we can't go to that family's house for a visit because they have a swimming pool, and Marios will get in the pool. Umm "no, I will look after him, don't worry", you know. (…) Yes. They were telling me, "no, no, the child is fine, you can see it". You know, because you can't see an issue just by looking at him …

Elena, mother of a 10-year-old child diagnosed with autism

The mother describes how she informed the extended family about the child's diagnosis gradually or selectively, because she believed that there would not be much understanding on their part. Specifically, the mother testifies an excessively optimistic reaction or a tendency to minimize the child's issues from the grandparents. Other parents decide not to share or involve the grandparents at all to their child's diagnosis because they would not understand or it would cause them unnecessary stress (*Y. Okay, the … to be honest, I haven't told my parents anything. (…) Because … I think it would stress them out for no reason*).

Apart from the misunderstanding, another common argument of parents is the denial of the diagnosis by the grandparents, suggesting there is nothing wrong but the child is just being naughty, which seems to distress the parent. Some parents have to face directly this grandparents' denial (*A. My dad is like, "there's nothing wrong with the baby" … "come on" and "it's nothing" and "it's okay, the child is fine". Umm that's what he told me every day, "there's nothing wrong with the baby").* The mother in the following extract explains how questioning the diagnosis may trouble the parent:

C. What bothers me when it comes to my mum and my mother-in… – not so much when it comes to my mother-in-law because she doesn't know, more so from my mum – is that sometimes, in her own way, she questions the diagnosis (…) And you feel that, "okay, am I that stupid?" Or have the doctors lied to me or … or maybe there's something I don't see, or that the child transforms, because when my mum has Antonis, he turns into a saint. Umm that's … that's just my mum's narrative, right?
ED. Yes.
C. Hehe (chuckle). And … that bothers me. I don't want anyone to question the diagnosis.

ED. Does it feel like they question your own effort as well?
C. The whole package. And mainly that I … I can't … I don't want to feel like a fool. As if someone tricked me. (…) You could say that it's a selfish issue as well, after all. And because, okay, I have invested so much, guided by that diagnosis.

Christina, mother of a 7-year-old child diagnosed with autism

The mother explains how the questioning of the diagnosis by the extended family impacts her. Denying the diagnosis hurts the parent's ego, as it raises questions or possibly makes her feel like she has done something wrong concerning the assessment of her child.

Demetra, in another narrative, vividly describes how upset she felt, nearly insulted, because of the implied cancellation of the child's presenting issues by the grandmother, as if she is wrong and not fully aware of her child's issues: "*And her reaction was, you know, this is traumatic to me as well, having to, to … accept that my child differs from other children. And her reaction was … something like, 'come on now'.* (…) *And … in that moment I thought, okay, do you think that … let's say, that everything I'm telling you is made up? Am I such a masochist (emphasized) that I make this up, and I enjoy telling you that my child is different from the rest? And also that umm, she is different in a disadvantageous way?".* The questioning of the diagnosis by some significant others, such as family, is like questioning the mother's attempt to understand it and her struggles to accept that her child is different.

5.3.2. Loneliness and distance

The child's diagnosis does not only affect the parents' relationship through conflict but also through distancing. This is what the mother describes in the following excerpt:

E. Sometimes I wonder how much longer I will be able to withstand this. Because Sophia's issue creates some sort of alienation at home, umm with your husband you … I don't know when was the last time we've been on vacation. Or when we last went out. So, inevitably, there's also this … this alienation.
ED. It affects so much, so many aspects.
E. Yes. It might have been there either way. Maybe alienation would occur too. But I can't say that I have been supported much … by my husband. Assistance, yes.
ED. Practical.

E. Yes, practical. Look, he will take her for a walk, or I will bring him the laundry and he will hang the clothes to dry. He helps in this way. Not as much as I would like or umm …
ED. Or as much as you need.
E. Or as much as I need. But what … I need a different type of support, more …
ED. More emotional support.
E. Emotional support, yes, I don't receive that. Sometimes I wonder, "how much longer will I be able to withstand this?"
ED. Yes, yes, yes. Umm from what I understand, your husband, approaches this in a different way.
E. Yes, I think he approaches it in a more relaxed way, maybe he hasn't understood this yet, or he doesn't express himself. I mean, how difficult, that this is still manageable since she's still young, and we will have to face more difficulties later on. Maybe he doesn't want to express this, I don't know. Umm … or he does, he hasn't realized it. Or he does understand it, or we also avoid it too. Sometimes I avoid even talking about it … the future. I think "I should focus on what needs to be done … now".
Eleftheria, mother of an 11-year-old child diagnosed with autism

The mother uses the term 'alienation' to describe the change of her relationship with her husband, the distance between them and the loneliness they experience. Their relationship is now limited to a procedural level, providing some practical help but nor spending time together or feeling emotionally satisfied. How everyone feels about the child's diagnosis is not even discussed (*Maybe he doesn't want to express this, I don't know*), since there is no meaningful interaction between the couple. This distance places emotional pressure on the mother, feeling that there is no one from whom she can draw support.

Other parents also describe a lack of any meaningful relationship, as if there is no longer a relationship between the couple, as if the relationship has disappeared or been absorbed by the full devotion to the child with disability (*E. On my own. (…) Lambros abstains, um he abstains. He abstains. I don't know, I don't know why he thinks that I can hold the fort on my own. (…) So, you see how it is for me as a person who is so focused on her kids, umm so on-task. I may tell my husband that I am not as much. Not at all. (…) but it's okay, he has accepted it, heh (smiles) I am so attached to my children, umm I am really anxious about them (…) really nit-picky. (…) Look, my husband is away most of the day*).

The diagnosis of the child with disability affects the family dynamics at the level of relationships, as well. The father in the following extract explains how he experienced this change of relationships:

N. When, when the baby was born, I was withdrawn, I didn't help, I didn't, I didn't, I didn't. Now I am more involved, I go to her school, to speak with the teachers, umm … um even take Natalie to the bus, help her sit in the bus, umm … I used to let my wife do everything. I felt withdrawn and … she noticed it too. (…) I used to come home, maybe not even say hello to her, took a shower, and so on, talked to Marilena, to my wife, and didn't talk to Natalie. Well, now everything has changed.

Nicolas, father of a 5-year-old child diagnosed with congenital brain disorder

Nicolas, father of two girls, admits that he distanced himself from the child with disability from the beginning. Without examining the reasons, he discloses that he had a different attitude towards the child with disability compared to other family members, essentially ignoring the child. The father's attitude signifies the representation of disability as a negative trait, which whoever carries it is not worthy to relate to others, and actually to one's own family. Additionally, the father introduces the representation of the child with disabilities as an invisible person for him, adopting zero interaction with her.

Other parents claim that the family dynamics and the relationship between the family members changed in a different way. The mother in the next narrative explains this change:

E. … I think that the way we were at home, umm and how things still are, umm is that Steph, I mean Christoforos, is not burdened by Stephanos' issues. Christoforos has his own life. He has his own room, that is his own space … Stephanos does not invade Christoforos' space, because he knows that it's his. Even if he breaks stuff in the rest of the house, he doesn't touch anything in Christoforos' space. Umm and we have this tactic in our family. That Christoforos um carries on with his own life. (…) I believe that his own mental condition is really important. So Christoforos has his own life, we carry on like this. It's just that his life has been affected by the things we could have done as a family, things that we don't do as much as we could have.
ED. Yes, yes.

E. It is very limited. So, we have shared the responsibility, Lambros takes him with him, they go out to eat, we go umm … we try to go on vacation in places where both can be catered to …
(…)
E. Yes. Umm at the moment, we have found a good balance. This balance means that umm, everyone has their own space. If his dad wants to do anything work-related on a Sunday, he can do it. (…) Umm I am used to how things are, that "okay, this is our life", I will take Stephanos and leave.

Elena, mother of a 10-year-old child diagnosed with autism

Elena, mother of 2 children, describes how the relationships within the family have changed, where essentially the father takes care of the older one and the mother takes care of the child with autism. Relationships between family members are selective while each family member strongly functions as a unit, as if the element of interaction between them has been removed. However, since the priority is to meet everyone's needs, this family dynamic seems to "work", thus the mother refers to this family model as balanced.

Some parents discuss how the child's diagnosis affected their relationship with the other child of the family. The mother in the following extract explains how this relationship changed:

I. Because it is really difficult. I went through really difficult times.
ED. Yes.
I. Not to mention that they are twins. While Nickie was normal, umm …there were moments where, for example, I got off work and picked them up from school, and it was when Nickie couldn't gain weight, so Nickie needed to be loved, to spend time with her. Nickie couldn't eat. There was a time when she was skin and bones. She kept losing weight. While I hadn't realized it. (…) I've made a lot of mistakes.

Irene, mother of an 11-year-old child diagnosed with cerebral palsy

Irene, mother of twin girls, one of which diagnosed with cerebral palsy, confesses with regret that she had neglected the child without disability. The demands of everyday life and the needs of the child with disability draw all the care to the one child, resulting in the other receiving limited attention from her. Quite a few parents report the same imbalance of care, where the child with disability receives most of the parents' attention, time and energy, resulting in the other child in the family losing something from the parents and always coming second in priority (*T. Umm truth be told, ever since Petros was born, umm … Pavlos has certainly missed out; A. The younger one joins the 'party', since he is usually left out*).

Loneliness concerns the parents' social life as well, since some parents report feeling isolated and excluded. The mother in the following narrative illuminates this sense of isolation:

E. Umm the treatment I received was that umm okay … of course they weren't inviting us, um because Stephanos is hyperactive, he jumped from couch to couch, ran around and so on, umm of course we stopped interacting. And I certainly, umm didn't receive, umm a call from anyone, asking me "how is Stephanos doing?", "is he okay?" I didn't even need them to ask "do you need anything?" No, no, no, I don't need anything, heh (smiles). Umm "how is Stephanos doing?" Do you know how happy that makes me? Someone asking how Stephanos is doing? He is fine! Let's say, yes, Stephanos really does exist! He is fine, yes, I am glad when they ask me how Stephanos is doing. (…) … and suddenly, because unfortunately umm – unfortunately? I don't even know if it's a good thing or a bad thing, heh (smiles) – umm you are forced to withdraw from the daily life you used to have. Umm I lost a lot of friends too. Because I didn't want to watch this, "ah, tonight we will go …" (…) I lost a lot of people from my close circle of friends. I experienced loneliness. Umm … but you necessarily disappear, because you can't keep up. And everyone else keeps going. Umm they may remember of you … but they don't have to live with this issue. Umm they keep living the way they used to.

Elena, mother of a 10-year-old child diagnosed with autism

The mother describes how her social life was diminished after her child's diagnosis as she can no longer follow the previous rhythms. Although she discusses it with a sense of bitterness (*I experienced loneliness*) yet she seems to rationalize this transition. Other parents also report that they stopped being invited to parties, which is how they realized their social isolation (*A. … before having our babies, we were invited to birthday parties (…) after giving birth to Petros, we were not invited ever again*). Another interesting point of this extract is the representation of the child with disability as an invisible person (*yes, Stephanos really does exist!*), like Nicolas discussing about ignoring his child in a previous extract. The mother here confirms that it makes her happy to be asked how her son is doing. It seems like the minimal human interaction is not taken for granted for the child with disabilities or is a kind of privilege for people without disabilities.

5.3.3. Support and connection

The social repercussions of the child’s diagnosis are associated, for some parents, to family or social support and extra family bonding.

For some other parents the diagnosis and the experience of parenting a child with disability had a positive effect on the couple's relationship. The father in the next narrative exemplifies this view:

M. (…) I’m not going to say that there’s anything positive, aside from the fact that … umm Christina and I are somewhat … closer, right? There’s a connection and … umm … not only a cooperation but there’s also a bond now. Umm it's certainly because I started looking after my child more than I used to. Yes, that’s a positive.
ED. Mmm.
M. Okay, that’s a positive, because before Antonis’ issue, I was less involved. Of course, as I said, me living in Athens also played a part … I would have definitely been more involved.
Marcos, father of a 7-year-old child diagnosed with autism

The father presents how the experience of the child's diagnosis brought him much closer to his wife. Other parents discuss this kind of support between the parents (*I. …me… and my husband supported each other very much*). Though, the father feels the need to emphasize that not only did the relationship between them improve, but they reached an unprecedented point of connection between them. Parenting a child with autism is a unique experience, which according to him gives the couple strong emotional resources and a special bonding experience.

Some parents report that the child with disability "united" the family. The mother in the next narrative exemplifies this perspective:

ED. Do you think that what you told me about the family bonding happened because of Christos?
M. Yes (…) He makes you a better person. (…) He gives you that love that bonds … that bonds everyone. That’s how I understand it. That Christos was the connecting link for everyone.
(…)

ED. … in which aspects does it make you a better person.
M. In everything. The way you think, very much. You don't only think, "ah clothes, shoes, decorations, this and that". You think deeper, more … in a more humane way. (…) Because they love each other. You hear so much. Others fight, they don't talk to their parents, they do this or that, they get angry about financials, this and that. But in our occasion, this has made the family bond, we are closely knit. (…) I feel that … this child makes us bond.
Maria, mother of a 6-year-old child diagnosed with Down syndrome

Maria, mother of 5 children, with the younger being a boy with Down syndrome, describes the child with disability as the link of the family. Since the birth of the child with disability, the emphasis is placed on more essential issues than to unimportant ones, focus which generates more connection between all members of the family. The father in the following extract confirms the same feeling:

V. I think that, okay … there is isolation, you miss out on family time, like I've said before. But the opposite happens as well (uses hands to show). Yes. Umm … I think it bonds you (emphasized) as family. It fortifies you.
ED. Aah!
V. Umm you may not have that … you may not have what you call your own space, your own time alone. Umm a couple who is like that though, they may be together in a room, and also have time to themselves or time together. Umm … one of them can just open the door, for example, and go somewhere else, to do, to … so … it's more open.
E. Mmm. Mhm.
V. Whereas this issue, locks you in as a family. (…) Umm … Yes, if you view it like this, from that perspective, it makes you … umm you feel more closed off. So, the coverage for the family's activities isn't all (emphasized) of Nicosia. It's within a smaller area. It's more … It's our home, … it's … So, our circle is smaller …
ED. More limited.
V. Yes. It's more limited but it's always … the more that space shrinks, the closer you are to one another (smiles).

Vasilis, father of a 6-year-old child diagnosed with autism

The father explains this family bond as a form of extra "safety". Dealing with the issues of the child with disability brings the parent closer to both their partner but also to the rest of the family. Therefore, the functional "space" of the family is eliminated and, as a result, family members come closer, forming a stronger bond between them.

Other parents report that they actually received a lot of support from their parents, practical but also emotional. The mother in the following extract discusses the support she had from her mother:

A. Umm I think because my mum knew that something was going on, umm even now, she makes me feel good for having Philippos. "He's great, okay, he has his difficulties but". (…) My mum will congratulate me, and if she tells anyone about us, she will say, "Antonia looks after him, she is making an effort, and Philippos has made tremendous progress". My friends do the same, so does my neighbor, and we are …
ED. Umm … and how, how does your mom's reaction make you feel?
A. I think she is a companion. It's good to know that I have her … I don't want to let her know that I may be crying, I won't tell her because I don't want to hurt her. I want to tell her about Philippos' progress, give her positive feedback, make her happy.
ED. Yes, yes, yes.
A. Sometimes I may be in despair, and I may tell her "pff I have Philippos". But she will try to soften things up by telling me … "he is making an effort, don't talk about him like that".
Antonia, mother of a 6-year-old child diagnosed with autism

The mother describes the support she receives from her mother, mainly on an emotional level. The understanding of the problem from the beginning but also the recognition of her efforts has led her to feel her mother as a strong ally. The mother's narrative projects a feeling of safety with the presence of her mother by her side.

This feeling of safety but also of sharing with their parents was highlighted by other parents as well. Christina gives an example of this consideration: "*my mother is also close to me. And my parents (…) Umm … I think we became companions on the road to realization".*

Some other parents discuss the good intention of the significant others, although they might experience some kind of conflict with them. The mother in the following narrative exemplifies this perspective:

A. Umm … Look, umm … I didn't say anything most times, because the other person thinks that they are being helpful by telling you, they think that they are being supportive, but the opposite happens. (…) Umm he told me every day, "there's nothing wrong with the baby". That's what I'm saying, that he thought he was being helpful, but it made me mad. There were times when I told him "dad, the baby has Down syndrome, why are you saying that there's nothing wrong?" What he meant to say was that, "okay, he has Down syndrome but it's not a big deal".
ED. It's not something …
A. I was just angry at his way of telling me that.

Andriana, mother of an 8-year-old child diagnosed with Down syndrome

Andriana discusses the indirect kind of support she received from her father. According to her, it is very important to identify the intention behind the claim "there is nothing wrong with the child". By acknowledging that her fathers' purpose was to help and not to prove her wrong, she realized the meaning of his words, which was "there is nothing wrong with having Down syndrome". This good intention ultimately determines the parent's reaction towards the grandparents' behaviour regarding the child's diagnosis.

Some parents confirm that they feel reward and praise from the people around them and from the broad family. The mothers in the following group discussion describe this kind of recognition:

E. (…) But those who do know about it tell me "I admire you standing on your own two feet and fighting for your baby". That's about it.
I. Well, they also said this to me, many times.
E. It's important to hear this though.
I. "You are so patient, well done".
(…)
An. Superwoman (chuckle)!
Mn. We need a pat on the back. We really do.
(…)
An. Umm … that's what I'm saying, "superwoman". Umm … "You go to work, you take care of things at home, you look after your baby, the way others don't do for theirs".
(…)

Mn. Umm … People close to me, close to us, behave the way our friend, E., says, they … they congratulate us. They say, "well done", for example, "you take good care of the baby", that we are worthy (sighs and smiles).

Evangelia, Irene, Anastasia, Marina (group discussion)

The mothers in this narrative argue about the importance of being rewarded by significant others. Rewards and praise have a direct impact on the mothers' self-esteem (*that we are worthy*), generating confidence for the effort they make, an effort that is greater than usual.

In terms of close friendship, parents distinguish between remaining friends and lost friends precisely because of the particular family circumstances generated since the child's diagnosis. The mother in the following narrative describes the support she received from a close friend:

G. Only with one of my friends. I have a friend with whom I had a great conversation and we ended up … my friend ended up accepting my baby the way he accepts me. There was a … they played together, whereas he usually doesn't play … (…) They may play together, they may (…) Or she happened to … she has other friends with kids, and she also invited me to her home for lunch, and I told her "I'm not coming because, well, he may bother you in your home …", and she told me "no, you will come, why would he bother me? You're coming". Whereas on other occasions I may say to other friends, "no, I'm not coming, you should come because, well, I prefer being in my own space, just in case he does anything it'd be … umm it'd be in my house, in my space, I won't feel as if …" And they say "okay", and they come over. She's the only one who tells me "no, no, you should come, and even if he does anything it's gonna … there's no problem".
ED. So she has accepted you fairly, let's say … just like the others … just like any other family.
G. She told me, for example, "what is he even going to do".

Georgia, mother of a 5-year-old child diagnosed with autism

Georgia discusses how she felt accepted by her friend when she and her son with autism were welcomed to her place. Compared to interacting with other friends, where the mother has to provide solutions for the child's challenging behaviour, this friend accepts them along with the child's issues. Consequently, the mother feels accepted and included. This kind of acceptance is critical, since it helps the mother minimize the child's challenging behaviour.

Feeling included seems to be very important, mentioned by other parents as well. The acceptance of the parent and his/her child as something familiar and not different (*E. what my friends often tell me is "that's what our children do as well"*) impacts the parent's sense of inclusion (*E. … they didn't isolate me*) but also contributes to the possible limitation of his/her anxiety about the child's issues.

5.3.4. Stigma

The way parents experience the raising of their children with disabilities within the social context reflects the social implications of the child's diagnosis and, by extension, the stigma they are found to experience at times. Firstly, the parents report *feeling stigmatised* in several ways because of their children's diagnosis. The stigmatising behaviour might originate from third parties, from professionals or from the extended family as well. The other main pattern emphasized in the parents' narratives is *the stares of others* towards their children or the parents themselves, which they describe as a frequent phenomenon. Parents seem to rationalize and not to feel disturbed by the stares of others, yet some parents believe that it is impossible not to care about people's comments in the social context.

In the broad social context, the parents often state feeling stigmatised because of their children's diagnosis. The others usually do not understand the child's behaviour, reject or may even offend the child. The mother in the following narrative describes a stigmatising incident towards her son:

E. I don't go around trying to hear what people have to say (…) I will only (emphasized) reply if anyone addresses me directly in a slightly harsh manner. Like I did at the beach once, if I remember it right, when Stephanos got in the sea. It was a weekday, and I went there with him, and he was jumping in the water … Okay, he was jumping up and down. Well, a mother, her little girl and another woman were close by. And Stephanos saw the girl, so he tried to approach her to share his … happiness. So just because he was jumping up and down in the water, and saying "aαh" and so on, that mother pulled her child close to her, umm when she saw Stephanos getting closer.

ED. Yes.

E. And I thought to myself, okay, maybe she doesn't know, right? I mean, she couldn't have known why he was behaving like that. And I told her, "okay, don't, umm he has autism and umm he feels nice in the water and he expresses his happiness". And the answer of that Cypriot mother was, "well yeah, but that's not my problem". Umm … and my reply was, "I understand, because your own problem is bigger, and you have to go talk to someone to see how you will sort it out".

ED. Hehe (chuckle).

E. I mean, I don't give a crap about them, sorry for the expression.

ED. She really told you that?

E. Yes, it it's not a big deal. It doesn't even bother me. No, no, if you think it bothers me, it doesn't. Not even, um if some woman stares at Stephanos, umm whenever, when I realize it, I just turn around and stare at her too, you know, with a blank stare. And it makes them feel uncomfortable. I don't mind the way they stare, um if they don't know.

Elena, mother of a 10-year-old child diagnosed with autism

The mother describes an incident where a girl reacted with fear to Stefanos' behaviour. However, what seems to have disturbed the mother was the reaction of the girl's mother, which strengthened the fear and prejudice towards unusual and different behaving people. The mother's frustration may also be related to the attempt she made to explain, which was declined by the other mother. It is interesting that the mother emphasizes that she doesn't care what others say, yet her description shows that she was disturbed.

A large amount of such reactions of others are related to ignorance regarding disability issues. The father in the next narrative discusses this matter:

M. Umm if it's someone I don't know, like for example on Facebook, where I was part of some discussions and … someone wrote to me umm "Down syndrome is caused by incest".

ED. Ahh (exclamation of disapproval)

M. Hehe! (chuckle). I started that discussion umm … if that person was in front of me, I would have killed them without a doubt.

ED. Yes, that's what you also said about knowledge. How ignorant can people be?

M. I explained it to them … Yes. I explained it to them. I replied to them, said that, "being semi-literate is worse than …", being semi-literate "…than being ignorant", something like that. Anyway. And we got into an argument. I told him, "my man, do you even

understand? I have five children. With the same woman". "There was no incest for four of the children, but there was for the fifth one?"
ED. Hahaha! (laughs)
(…)
M. I try to tell them. Because … And I try to be understanding towards them, because before Christos was born, I didn't know either what Down syndrome is.
(…)
ED. Umm how did that Facebook discussion you told me about made you feel?
M. Awful. Because aside from people not knowing, they also say stupid things.
ED. Yes. Yes. Did you get angry?
M. Yes. Yes. (…) When people stare, they see something out of the ordinary, right? Christos certainly looks different than other kids. Umm Down syndrome is obvious when looking at someone. So, they know it's something different. It doesn't bother me when people stare.
Marios, father of a 6-year-old child diagnosed with Down syndrome

The father chooses to discuss about Down syndrome in several conversations, even with strangers, as he recognizes people's unawareness, a position that he found himself before having his son with Down syndrome. However, sometimes the comments he receives are offensive and anger-inducing. Despite his anger, the father continues to argue. His attitude denotes a kind of defense towards his son and towards people with disabilities in general: there is nothing wrong with people with disabilities but much more it is not their fault nor their parents.

The stares of others are a phenomenon often reported by parents. The father in the previous extract finds them justified, due to the syndrome's special characteristics, which stimulate people's curiosity. On the contrary, the mother in the next extract, does not share the same understanding:

A. Umm … basically, the biggest issue when dealing with a disability is people's attitude, and not the disability itself.
(…)
A. It doesn't cross their mind that, yes, there are difficulties, life is difficult, but in general, life is the same … you face the same things others do. For example, on the three-day weekend … it wasn't three days, it was the October 1st national holiday, umm … we took the day off on Friday and we went to Paphos for four days. There were 900 Cypriots in our hotel. I knew some of them … I mean … (…) And I felt like some of them stared at us as if to say "they are here too?" Yes, even people like us, who have children with Down syndrome,

go on vacation. We also stay at hotels, we also go to water parks. Hehe! (laughs). Wow, right?
ED. It's as if they were telling you "what are you doing here?" (chuckle)
A. Yes, like saying "these people come here too …". Yes, I do come here, what do you want me to do? Lock myself inside a cave, for example, just because my baby has Down syndrome? Am I hiding or something? Of course not! I live the way others do.
Andriana, mother of an 8-year-old child diagnosed with Down syndrome

According to Andriana, the main challenge in her social interactions is that people face persons with disabilities as something different, while the people themselves and their families live an ordinary life like everyone else. The representation of people with disabilities' lives as normal contributes substantially to the deconstruction of the diversity of persons with disabilities and their families.

The mother indirectly also raises the issue of the isolation of people with disabilities, breaking this myth as well and emphasizing the aspect of pleasure and fun in people with disabilities' lives. Like all people, people with disabilities need satisfaction and entertainment in their lives. This matter is directly related to the sociocultural conditions where people with disabilities, especially with mental and/or intellectual disabilities, in Cyprus are found to live very isolated.

Other parents report that they have experienced stigmatising behaviours from professionals. The mother in the following narrative exemplifies this treatment:

A. We may get weird looks in the park. And we may get weird looks if he does something he shouldn't. Which is acceptable. But up to there. Someone feeling pity … I only experienced that a few times.
ED. Yes. Umm do you remember an occasion where you experienced someone feeling pity for you?
A. Feeling pity? (nervous smile) When we went to the see an eye doctor. In Greece. Umm when he doesn't co-operate in these places. When I told her assistant before (emphasized) that they should give him eye drops, because "Philippos has autistic characteristics and he needs more time", and she said "aw, I'm sorry about that" (sighs, puts her arm on her chest, in an exaggerated/pretentious way) "Did you recently find out?", "Umm" I tell her. "I'm so sorry" (smiles). Yes. I felt that really intensely.
ED. How did you react?

A. Umm I don't think I react appropriately. I didn't say anything. What was there to say? (…) Yes, because sometimes … And because, okay, in some places I am really anxious for the tests to be over … for him to co-operate so we will get out of there. (…) Yes. And the headmistress of the private kindergarten I sent him to, used to tell me "this kid" (awkward smile). "These kids". "What can we do?" "These kids".
ED. Which is somewhat like … generalizing.
A. I don't even bother with her. Yes.

Antonia, mother of a 6-year-old child diagnosed with autism

The mother describes how, apart from the looks of others, she feels sometimes embarrassed by the behaviour of the professionals. Specifically, she reports that some professionals project to her some kind of pity, through a hypocritical rather than genuine interest. The mother seems to be bothered by certain clichéd phrases about people with disabilities, which are often used in the public discourse ("*these kids*"), making her feel a one-size-fits-all treatment. This behaviour provokes the mother's sense of her child's uniqueness and seems to deeply annoy her.

The reactions of others regarding the child's diagnosis sometimes derive from the extended family. The mother in the following narrative chooses to disclose the diagnosis to the broader family but it's a big matter whether the disability is visible or not:

A. No, I talked about it, I had no issue … with … why would I hide it? I know people who still try to hide it, even though their child is five years old … You can tell, you guys. What do you mean 'anyway'? They should accept their children the way they are (…) What are you trying to hide? It is obvious. Or what they used to tell me quite often, because Petros was a beautiful baby (…) And everyone told me "well, he doesn't look like he has it". "He doesn't look like he has it". "He doesn't look like he has it". I simply exploded at one point, and said "you guys, I don't care!" (emphasized) My family were the ones who used to tell me this. I don't care if it looks like he has it. I don't mind if it looks like he has it.
ED. Yes.
A. I wish he didn't have all those other issues, like being eight years old and still trying to speak, he hasn't yet, he was almost four years old when he was able to walk. We don't lose hope of course, but for me, these are more important than whether he looks like he has it. I don't give a damn if he looks like he has it (…) I don't give a damn.

Andriana, mother of an 8-year-old child diagnosed with Down syndrome

The mother describes how she openly communicated her child's diagnosis, since as a visible disability she considered it completely useless to hide it. The attitude of others, though, in the wider social context, for instance the need of some parents to hide their child's Down syndrome, testifies to a profound sense of stigmatization of people with disabilities and their families. The reaction of the extended family to the mother herself – using the child’s invisible disability as an argument – although probably aimed at comforting her, provoke her feelings of anger. The whole discussion of visible and invisible disability, whereas the mother seems to strongly disagree with it, seems to reflect the level of felt stigma (discussed in chapter 2.2.3.) experienced largely within the society around the mother.

As mentioned by other parents (Marios and Antonia) above, the stares of others towards parents seems to be a frequent phenomenon in the public sphere. The father in the next extract explains this attitude, discussing the matter from a different perspective:

M. I remember there was an occasion … when a granny said, “you have lost it with the kid” (…) This happened 2-3 years ago. “Excuse me?”, I said. She said, “you’ve lost it with your kid”. “You don’t control him”. “He controls you” (…) Okay, you know. What I’m saying is that umm … I’ve experienced it, you know, he gets scolded a lot of times (…) They say that he is spoiled. (…) We feel awful when he doesn’t behave the way we would like him to. I don’t know … he has a tendency to want to hug his mum, he is now seven and a half years old. Umm … inside a church … it’s too much, I mean … we should have some manners. It’s also a social issue, it matters.
ED. Yes, hmm.
M. It’s better if he … doesn’t do it. We feel bad about ourselves. Umm … and for the child.
E. What do you mean?
M. Look. Everything matters. Everything matters. You can't say that … umm even if you are perfectly conscious, you think that it would be a lie if you say that you don’t think of others. That you don't think about your social standing (…) honor is a primary concept in Greek society. Honour [word said in English]. Okay? What we discussed about conscience etc. How others view you. It matters (…) So you think about it, to a certain degree. Okay? I wouldn't say it defines me. That it determines how I will behave to Antonis, or what Antonis does. Okay? About what, about how others view us, excuse me. Okay? Because of Antonis. At the very least, I try not to let it define me

Marcos, father of a 7-year-old child diagnosed with autism

The father shares an incident where he was criticized in public for the way he is parenting his child. Several of the parents' narratives contain the element of criticism towards them, concerning that they have done something wrong as parents, like spoiling the child or other. However, the father admits that it’s impossible not to care about people's comments. According to him, we live in a society where, consciously or unconsciously, we are always concerned with the image we project to the social context. And when his son with autism presents challenging behaviour in public, this can have a negative impact on him.

5.3.5. Summary

The parents’ experience of raising a child with developmental disability is placed within the broader social milieu, indicating as part of it some implications regarding the milestones of the diagnosis for the parents. First of all, the diagnosis is not one-dimensional but it is approached from different perspectives by the two parents. Some parents report how the diagnosis caused conflict between the couple and evoked different emotional reactions and different perspectives as to how to handle the new conditions. Regarding the extended family, the parents stated that they experienced limited understanding or denial of the diagnosis, which triggered feelings of anger. The dynamics developed within the family often include loneliness and distance between the couple, selective interaction between family members but also unwanted neglect towards the child without disability. However, some parents described that the diagnosis created a tight bond between the two parents or that strongly united the family. Most of all, though, the parents experience stigma in the way their child is treated by others – strangers, professionals, or significant others – and in the way they communicate the diagnosis to important others.

5.4. Bringing it all together

This chapter examines the milestones of parenting a child with developmental disability focusing particularly on the issue of diagnosis. Several aspects of the diagnosis can be considered important milestones in the parents’ experience: the announcement, the reception, the interpretation and the negotiation of the diagnosis with social others. I discuss how each of them relates to existing literature and how it contributes to that.

To summarize, the *announcement* of the diagnosis is the very beginning of a long journey which is experienced as an unstructured process, with experts appearing unprofessional and leaving a general negative memory to the parents. Parents' *initial reception* of the diagnosis is shock, experiencing the diagnosis as a traumatic event or even facing bereavement. Parents' *long-term reception* includes acceptance of the child's diagnosis, no acceptance and keeping some distance from the label of the diagnosis. Parents also described several factors that help their acceptance of the diagnosis.

Parents' *interpretation of the diagnosis* refers to understanding the diagnosis as a random event or as the parents' responsibility, which were the most common themes. There were also some parents attributing the diagnosis to God or other superior power and some others presenting interpretations related to medical factors.

The social dimensions of the diagnosis refer to the social dynamics that emerge in negotiating the diagnosis with the social others. Firstly, parents report different considerations, misunderstanding but also conflict within the close or the extended family. The family dynamics change tremendously from the moment of the diagnosis onwards, with a clear impact on the parents' relationship, differentiation among the family relationships, but also with social isolation. However, some parents describe feeling socially supported and more united as a family since the diagnosis of their child with disability. Stress and tension due to the high demanding daily routine is another pattern raised by some parents. As to the broad social context is usually stigmatising towards the family and the child with disability, mainly due to unawareness.

In what follows I am going to focus on the parents' ongoing process of relating with the diagnosis and argue about the parents' negotiation of the representation of the diagnosis as problem.

5.4.1. The ongoing process of negotiating the diagnosis

This study suggests that the parents' long-term reception of the diagnosis is an ongoing process of negotiating their children's diagnosis. What parents experience following the announcement and during their experience of parenting their children with developmental disabilities is not about acceptance nor resolution, as previous literature suggests.

Parents encounter a new and critical experience in their lives, the diagnosis of their child with developmental disability, which they are trying to negotiate. However, what does the negotiation of the diagnosis include? During interviews, I used the concept of acceptance, where the parents were asked whether they believed they have accepted or not their children's diagnosis. It is obvious that the parents themselves find it difficult to discuss and to analyse the idea of acceptance. Some parents answered with a question, wondering what accepting the diagnosis means. Acceptance is also represented by some parents as competitive or even cancelling their efforts regarding the child's progression, and thus accepting the diagnosis was not among the parents' goals. Other parents are sceptical to the need of acceptance, since they take some distance from the label of their children's diagnosis. Some other parents abandon the aim of acceptance when they restraint from the continuous comparison with the typical milestones of development. Furthermore, how parents negotiate the terminology around the diagnosis helps them – or not – to take a step further throughout this ongoing process of relating with the diagnosis, claiming actually that the labels don't really matter and might be disabling for the parent.

Therefore, parents are not concerned with the acceptance of their child's diagnosis, nor have as a goal to accept the diagnosis. Instead, parents experience a process that does not reach a certain point of acceptance or resolution. What parents describe is an *ongoing process of negotiation*, not the achievement of a realization regarding their children's diagnosis. There is not a landmark point or a phase where parents achieve acceptance. There is an ongoing process of negotiating the diagnosis, with specific characteristics. This process is developed gradually, differently and individually for each parent. I describe this process in the next pages.

The process of negotiating the diagnosis depends on each of the milestones of the parent's experience, with each one impacting on how the negotiation will proceed. How the parents initially experience the diagnosis, namely the announcement of the diagnosis, determines how the diagnosis will be negotiated along the way. For instance, some parents reported experiencing anxiety upon the announcement of the diagnosis, which placed them in a state of alertness and generally affected how they processed the child's diagnosis from there and on. A mother received the apologies of the professional, reflecting and communicating to her the child's diagnosis as a problem. The parent's interpretation of the diagnosis influences profoundly their negotiation on the diagnosis. For example, some parents acknowledge the responsibility they feel in relation to their child's diagnosis, responsibility which clearly determines the process of negotiating the diagnosis, with a strong emotional burden for the parents. The social dimensions of the diagnosis are also found to be decisive in the way parents process their relating with their children's diagnosis.

Some parents report feeling included from their social environment, thus they feel that their child is contained and has a place in society, which help them negotiate the diagnosis and keep going. Others, though, describe feeling stigmatised in the broader social context, which differentiates their negotiation, by isolating themselves and their children. Additionally, there are elements that help parents in this process of negotiation (discussed in chapter 5.1.4.) that also differ across parents. For instance, these elements may help parents to recognize the severity of the child's diagnosis or to relieve the parent from the comparison with other scenarios. Since the milestones are different for each parent, the ongoing process of negotiation results in a different individualized course of processing the diagnosis for every parent.

The process of negotiating the diagnosis is always a process forward, since parents cannot go back and undo the process. Parents report that since they are processing the negotiation of the diagnosis they cannot "take it back". The process of negotiating the diagnosis aims at a unique for each parent, functional for each parent, way of associating with their child's diagnosis in the present. Then, this process is again differentiated and transformed, building upon all previous phases of the process, since this is about an ongoing, never-ending process of negotiating the child's diagnosis. The process of parents' negotiation with the diagnosis is captured in figure 5.VI.

The existing literature fails to adequately describe the process experienced by parents in terms of their long-term reception of the child's diagnosis. Previous studies used the term acceptance, recently being followed by the term resolution. None of them, though, adequately captures the process experienced by parents. Additionally, there are no studies focusing on the ongoing aspect of the process experienced by parents.

What this research suggests is that acceptance does not fully represent what parents experience regarding their children's disability. The term acceptance has been criticized in literature as a controversial term, not capturing the process experienced while raising children with disabilities (Larson, 1998). Borrowed from the Kubler-Ross stages of grief model (1969), it is considered in the literature as a "blanket term" mainly used by professionals, often representing the first step in a healing process (Larson, 1998). The term also refers to the medical model of disability and the acceptance of the diagnosis which is experienced as a problem (McLaughlin et al, 2008). In this study, the term acceptance also appeared to be of limited importance or highly questioned by parents. In fact, parents barely mentioned this concept, except when asked, without particularly focusing on whether they have achieved to accept their child's diagnosis. Interestingly, sometimes the term acceptance was often confused to the acceptance of the child itself, i.e. if the parent accepts or rejects the child because of the disability or to the child's diagnosis, which most of the parents wishing not to had experienced it. However, parents do not introduce into the discussion the acceptance of their child as it is (child with disability), focusing instead on the process they experience while parenting their child with developmental disability.

As a response to the idea of acceptance, part of the literature uses the term resolution. Parents' resolution is about a process of acceptance, identified by the end of grieving regarding the child's diagnosis and the regain of the emphasis on present and future (Poslawsky et al, 2014). Parents are found to differ in how they cope with initial grief. As time passes, they tend to feel less intense negative emotions or denial and experience an increase in positive feelings towards their child (Sher-Censor & Shahar-Lahav, 2022). Not all parents achieve resolution, since some parents engage in continuous bereavement (Reed et al, 2019), experiencing more depressed and stressful feelings (Krstic et al, 2015; Sher-Censor et al, 2017). Parents who reach resolution acknowledge the reality of the diagnosis and the diagnosis' consequences, they integrate new information about the diagnosis but also consider their children beyond their diagnosis, maintaining a balance between the adverse impacts and the advantages of receiving the diagnosis (Sher-Censor & Shahar-Lahav, 2022). The parents who adapt better to this process are considered resolved, recognizing though their painful feelings regarding the child's diagnosis (Sher-Censor & Shahar-Lahav, 2022). Other studies presented parental resolution as a continuous process, involving adjusting expectations and managing emotions in response to the challenges of raising a child with disability (Barak-Levy & Atzaba-Poria, 2015).

However, despite being recognised as a process, resolution, as is acceptance, seems to be conceptualized in the literature as having a final outcome. *Once the parent achieves the outcome of resolution, there is nothing more to process or resolve.* Resolution might be a process, incorporating different aspects of the parents' experience – namely feelings and coping - but it remains a linear process, which once mastered, there is no continuity. Additionally, the resolution does not answer how the main milestones of the parents' experience are related, namely the experience of the diagnosis, the parents' interpretation of the diagnosis and the social dimensions surrounding the diagnosis.

The concept of parents' negotiation is not new in literature. Negotiation designates a process through which parents try to work through and understand their children's disability (Case, 2001). Vanobbergen et al (2006) introduce the negotiation model, according to which parents are negotiators of their children with disabilities, as they negotiate the communication between them and the representation of their disability. The negotiation model considers the family a space where the meaning about parenting and disability and the expectations of support are negotiated, extending in fact the parenting connections to communities beyond the family. Other researchers focus on the parents' negotiation following the life transition of the child's disability (Prasher, 2010).

However, the idea of negotiation as used until now, does not effectively represent what parents experience. The negotiation model of Vanobbergen et al (2006) seems to be closer to the idea of advocacy, where parents negotiate their child's disability in relation to the social context, without focusing on any experiential process experienced by the parents. Other research studies explore the negotiation of the parents' transition, without examining the overall process of the negotiation experienced by parents. The parents do not seem to outwardly negotiate their child's diagnosis but to experience an internalized process, which is complicated, ongoing and is not completed when adapted to the new transition. This process of negotiating the diagnosis is not always conscious for the parent and is related with the three milestones of the parenting experience, where my perspective on negotiation emerges.

What seems to be missing from the literature is how the above-mentioned milestones are related between them and are associated with the process experienced by parents. This study suggests that *all mentioned milestones are constantly present and determine the parents' process of negotiating the diagnosis*. The milestones are subject to possible changes – for instance, some parents might pass from the interpretation related to God to the one related to medical factors – but this change is the result of the process that the parent goes through. Parents' experience of the diagnosis, including the professionals' approach, plays a decisive role in how they will initially receive, comprehend, negotiate and finally process the diagnosis. McLaughlin et al (2008) argue that parents are active participants in their children's diagnosis, thus they are influenced but also determine the parenting experience regarding their children's diagnosis. Alongside, it seems that the parents' interpretation of the diagnosis is taking shape, which contributes to the processing of the diagnosis. Further, the social implications of the child's disability – namely how the social milieu responds to the diagnosis – seems to affect parents' process of relating with the diagnosis. Thus, the parents' process 'goes through' others, the close or the wider social context. All the aforementioned interactions suggest that this is about a complicated experiential ongoing process. In fact, it is a process based on the parents' total experience, individual, family and social experience. Involving the parent as a person, the family but also the family's world, it is obvious that this process is not exclusively an internal, but an eminently social process. Consequently, the parents' process of negotiating the diagnosis is a multidimensional internal and external process, a difficult challenge and a delicate balance between all dimensions of parents' life.

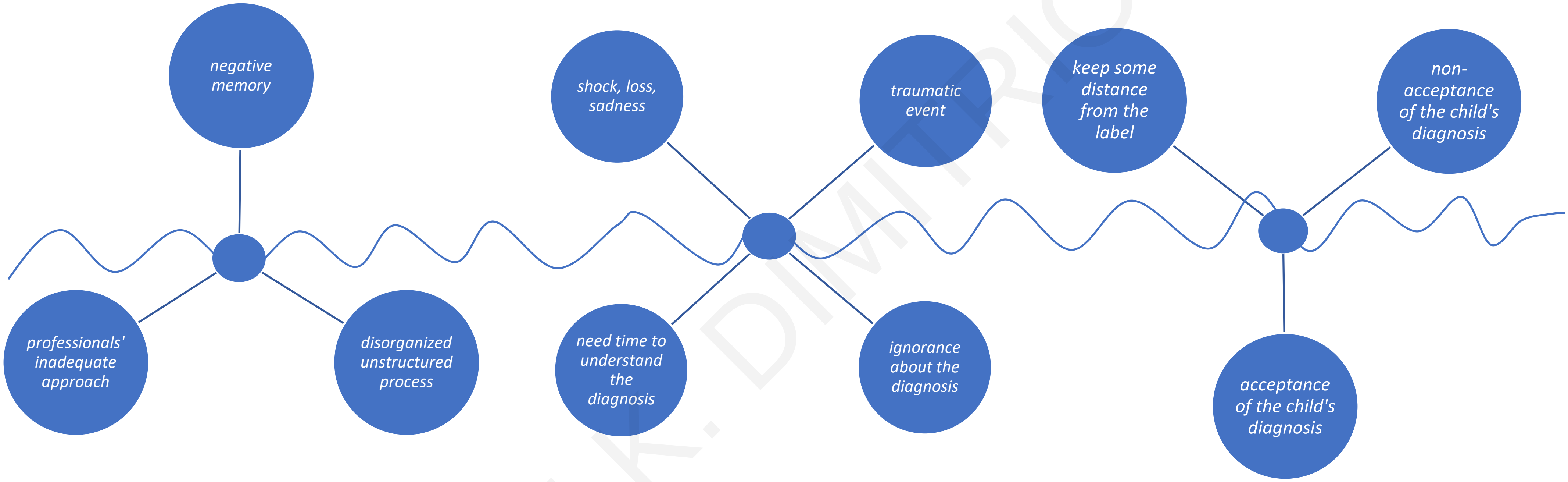

Figure 5.VI. The ongoing process of negotiating the diagnosis

Bringing it all together, the existing literature does not efficiently address the ongoing and multidimensional nature of the process of negotiation experienced by parents. Therefore, this study rejects the terms acceptance and resolution because they fail to describe the ongoing process parents go through as well as the distinct elements that this process consists of, namely the milestones of the parenting experience, namely how the diagnosis was announced to the parent, how the parent's interpretation is shaped in relation to the diagnosis and what are the social dimensions of this diagnosis for the parent. It is, also, important to note that this is a common process across parents who seem to describe a similar negotiation experience. Even parents who stated that they did not accept their child's diagnosis, they discuss experiencing a process of negotiating their children’s diagnosis.

This approach extends the existing literature by focusing on the ongoing and multifaceted nature of the parents’ process of negotiating their children’s diagnosis with developmental disabilities. By challenging the concepts of acceptance and resolution, I emphasize the continuous dimension of the process and I identify specific milestones determining the negotiation throughout the parental journey. However, this study recognizes the particular aspects of this ongoing process, namely how the diagnosis is communicated to the parents, how it is interpreted and is socially contextualized by parents. This understanding offers a more comprehensive perspective on the negotiation process experienced by parents of children with developmental disabilities, bridging gaps in the existing literature.

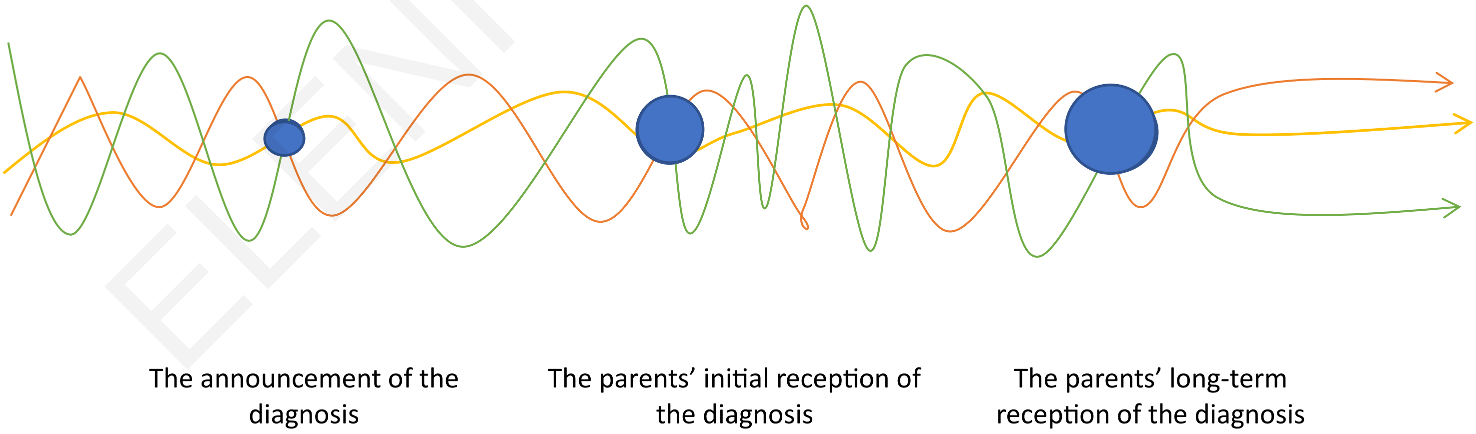

Figure 5.VII. The ongoing process of negotiating the diagnosis, involving the 3 milestones of the parents’ experience

5.4.2. Negotiating the representation of the diagnosis as a problem

This research suggests that parents initially represent their child's diagnosis as a problem. The process of negotiating the diagnosis (discussed in chapter 5.4.1) helps to develop a transition from a medical to a social representation of the child’s diagnosis. Thus, I propose that the parents’ repeated transition between the medical and the social consideration of their children’s diagnosis allows them to deconstruct the representation of the child’s diagnosis as a problem.

The parents, from the initial information they receive regarding their children’s diagnosis, namely the announcement of the diagnosis, and gradually as they are exposed to the issue of disability, at a social level, they repetitively receive the representation of their child's diagnosis as a problem. The parents’ representation of the diagnosis as a problem is obvious from the two milestones discussed in this chapter, the experience of the diagnosis (mainly the announcement) and the social dimensions of the diagnosis. It also reflected on the parents’ interpretation regarding the child’s diagnosis.

Regarding the announcement of the diagnosis, most interviewed parents reported that the diagnosis was communicated to them as a problem, as an adverse situation that they found themselves into. This negative representation starts, according to the parents, from the professionals, where almost everyone agrees that there is no professional using a positive rhetoric around the diagnosis issue, conveying to the parents anxiety and distress about the tragic event of the child's diagnosis. The way of the announcement was problematic, too, without the appropriate presentation but also without enough information concerning what the diagnosis is about and what are the parent’s next steps. Some parents reported that professionals apologized for the child’s diagnosis and some others that they developed hypothetical negative scenarios about the consequences of the diagnosis on the family. Additionally, most professionals seemed to focus on the negative aspects of the diagnosis, completely disregarding the positive aspects or the total picture of children with disabilities. Other professionals, according to parents, presented the worst-case scenario of how the child will progress or emphasized the permanence of the ‘problem’. Parents, also, described how the diagnosis triggered them questions, which could not be answered at the time, a fact which they attributed to the professionals’ inadequacy, reinforcing overall the problematic nature of the announcement of the diagnosis.

Concerning the first initial period of the announcement of the diagnosis, most parents report that their instinctive reaction was that their child has got a problem. In fact, some parents represent the diagnosis as such a tragic problem which can be likened to the loss of the child. Additionally, the parents describe feelings of loneliness, experiencing their children’s diagnosis as an individual problem and themselves being completely dependent on the professionals. Some parents illustrate a chaotic picture, being not at all appropriately informed. Furthermore, parents are asked to comprehend the diagnosis on their own, without proper support and given that there is no structured process of communicating and informing the parent about the diagnosis.

The parents’ interpretation of the diagnosis is also found to reflect the representation of the diagnosis as a problem. For instance, some parents describe the diagnosis as a punishment or a test sent from God and other parents as their own responsibility, related to their late intake to the maternity hospital or their age of reproduction. As to the social context, the diagnosis is well represented to the parents as a problem. The stigmatising discourse with which parents are confronted reinforces the representation of the diagnosis as a problem. Additionally, parents often report loneliness or not being understood, either because there is no shared understanding within the family or because the parents become socially isolated. Thus, parents come to terms with the fact that they are experiencing an individual problem, which they have to handle on their own.

The representation of the diagnosis as a problem by the professionals, to which parents are directly and broadly exposed, is largely confirmed by literature. The parents’ perspective on the professionals’ approach, is mostly described as leaving no room for hope (Kearney & Griffin, 2001), lacking empathy (Davies & Hall, 2005) or using tragic or pathological disability discourse (Goddard et al, 2000), which was described by interviewed parents as well. According to most parents, the others – extended family, friends or others – also act in a stigmatising way, unable to support or understand, behaving as something significantly disadvantageous happens in the family. The social circle around the family is limited, with parents being marginalized (McLaughlin et al, 2008). Additionally, the parents report that they didn't know much about the diagnosis, also proposed by literature (Brett, 2002), unfamiliarity which might raise feelings of insecurity regarding the child's diagnosis.

The representation of the diagnosis as a problem is largely consistent with the medical model of disability (chapter 2.1.1.), which approaches disability as an individual problem and a personal tragedy (Oliver & Barnes, 2000). It is based on the idea that people are absolutely defined by the concept of normalcy, a person's worth is solely related to physical characteristics and people who do not meet these criteria are arbitrarily degraded (Albrecht, 2006). The medical model of disability reinforces representations of people with disabilities as defective, weak, unworthy and inferior, thus what Albrecht et al (2001, p. 91) describe as the ‘presumption of disability as a burden’. Accordingly, parents’ discourses reflect a representation for their children being objectified, seen as passive and pathetic, dependent on the professionals and the family and overall represented as a problem (Oliver & Oliver, 1996; Barnes et al, 2001). Concerning the social context, an inferior status is accorded to people with disabilities and they are rightfully stigmatised (Brett et al, 2010). In fact, the social context seems to influence this representation in a circular way, as it contributes to the establishment of this representation. All of the above are general and pervasive within the social field, greatly impacting on parents' representations of their child's diagnosis and disability.

The parents are found to internalize these stimuli and gradually establish the representation of their child’s diagnosis as a problem. They describe and communicate their child’s diagnosis as a problem, as the ‘bad thing’ which happened to their family. The diagnosis, as a problem, has negative effects on each member but also on the family as a whole, as the dynamic changes, with the parents shouldering the full burden of this problem and testing their limits on how to withstand with such a problem.

However, the parents do not exclusively seem to be debilitated or negatively influenced by this representation. Instead, the parents may use this representation to their benefit. Specifically, Elena used this problematic representation as a motivation for action. Other parents report that the representation of the diagnosis as a problem help them to make sense of the diagnosis for the others, including significant others, such as grandparents. Other parents are troubled by significant others’ denial of the problem, namely the diagnosis, because cancelling the problem means cancelling the parents’ efforts as well. Therefore, the representation of the diagnosis as a problem contributes in a sense to the parent’s meaning making and the particular identifying regarding the diagnosis, so that the parent can have a clear picture and deal with the diagnosis of their child accordingly.

What this study suggests is that parents negotiate this representation of the diagnosis as a problem. Parents are not found to stay inactive in front of this problematic representation. Entering the broader social field as parents of children with developmental disabilities and while they are processing their relating with the diagnosis (chapter 5.4.1), the parents find ways to negotiate the representation of the diagnosis as a problem. For example, some parents seem to claim their children’s place in the social context, either by validating them as individuals, through their presence within the broader society or with their visibility as children with disabilities. Parents were also able to identify the stimuli received by significant others, which do not represent the diagnosis as a problem, effectively deconstructing the negative representations of the child's diagnosis. The interpretation of some parents also reflects this distance from the representation of the diagnosis as a problem, namely the interpretation of the diagnosis as a random event. Lastly, the parents report that, despite the problematic aspects of the child’s diagnosis (i.e. medical issues), the child can grow up and have a happy life, abandoning the problematic representation of the diagnosis

The parents do not take this transition all at once but gradually negotiate it as they experience their child's parenting. Consequently, I conclude that there is a long process where parents move between the medical and the social representations of their children’s diagnosis, integrating the stimuli they receive along the way, such as their interpretation or the social implications of the diagnosis (Figure 5.VIII).

Consequently, the parents initially represent the child's diagnosis as a problem, tending towards the representation of their children’s diagnosis as an individual, medical and adverse problem. Through constant negotiation and while the processing of the diagnosis progresses, the parents move between the discourses that the medical and the social model of the diagnosis suggest. The process of relating to the diagnosis (discussed in chapter 5.4.1) helps this movement between medical and social representation of the problem. Thus, I propose the parents’ repeated transition between the understanding that emerges from a medical and a social model of their children’s diagnosis, allows them to deconstruct the representation of the child’s diagnosis as a problem. Through the milestones of their experience – the experience of the diagnosis, the interpretation of the diagnosis and the social implications of the diagnosis – parents acquire skills and expertise, experience feelings and extend their perspective in order to transform the ‘represented as problem’ diagnosis into something else, such as action, hope or else. What parents seem to need is to transform this representation of the diagnosis as a problem to something else, by integrating the entire experience of parenting a child with developmental disability. This is what I discuss in the next chapter (chapter 6).

This approach of parents’ moving between the medical and the social representation of the child’s diagnosis – by using the terms medical and social representations as discussed above – is important because it *emphasizes the parents’ self agency*. Parents are found to be actively involved in the negotiation of this representation, unlike previous studies that often portrayed parents as passive recipients. Specifically, part of literature claims that parenting a child with disabilities often places the parent into a recipient role, receiving diagnosis, assessments or therapies (Beresford, 1994). On the contrary, this study suggests that parents move forward, distancing themselves from this passive role. It illustrates how parents negotiate the representation of their children's disability, actively engaging in social contexts, validating their child's individuality and asserting their presence within the broader society. This active negotiation challenges the stereotypical representation of the child with disability – as a tragedy, suffering and causing trouble to the whole family, and the representation of the parents – as overwhelmed and burdened by their child's diagnosis. This is consistent with previous studies, which question the tragic experience of parents raising their children with disabilities and argue about the adaptive characteristics and the positive aspects of the parents' experience (McLaughlin et al, 2008; Ellis & Hirsch, 2000; Murray, 2003). This study, similarly, concludes that parents don't stay passive or inactive regarding their children's diagnosis. They, rather, negotiate the representation of the child's diagnosis, attempting to assign it with a different meaning other than the representation of the diagnosis as a problem, which they initially adopted.

Another reason of this approach being important is the *deconstruction of the negative representation* of the child's diagnosis. Parents although receiving negative representations of their children's diagnosis, they manage to challenge the prevailing negative narratives, to question, to negotiate and possibly to reverse the representation of the diagnosis as a problem. Thus, parents manage to deconstruct the negative representations of their children's diagnosis, by identifying and rejecting the representation of the diagnosis as a problem. Without necessarily acknowledging it, parents might contribute to the reversal of the medical model of disability by questioning it. Additionally, this study highlights parents' attempts to construct a positive representation of their child's disability, despite the challenges posed by the representation of the diagnosis. This positive perspective seems to empower parents regarding their children's future and might also inspire them with a sense of hope and motivation.

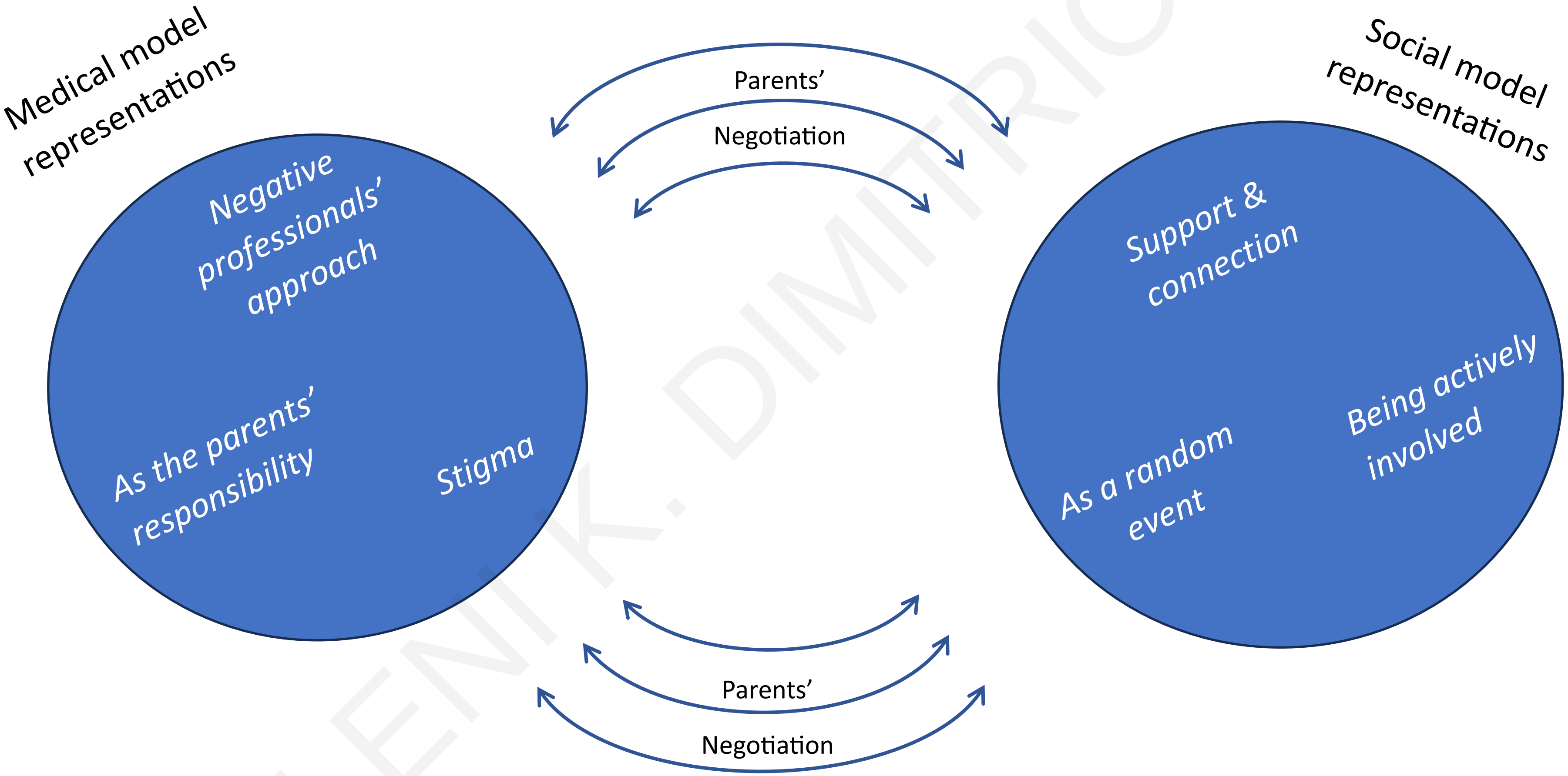

Figure 5.VIII. Negotiating the representation of the diagnosis as a problem

Overall, this study suggests that, while parents initially receive and internalize the representation of their child's diagnosis as a problem, they manage to negotiate this representation, by moving between the medical and the social representation of the child's diagnosis (Figure 5.VIII). In other words, parents strive to negotiate their children's diagnosis and their experience of raising a child with disability, against the backdrop of the social representation of disability as a problem and as a tragic event. To achieve this, they are found to utilize the representation of their child's diagnosis as a problem to their benefit and gradually transform it during their parenting experience, attributing a different and effective to them meaning of their children's disability.

This suggestion of the parents' negotiating their children's diagnosis is important because it emphasizes the parents' self agency and sense of control, being actively involved in the representation of their children's diagnosis. Additionally, this approach seems to contribute to the deconstruction of the negative representation of the child's diagnosis, challenging the prevailing negative discourses leading to the representation of the diagnosis as a problem.

Chapter 6: Parents’ personal experience

This chapter aims to illustrate how parents of children with developmental disabilities represent their parenting experience. Particularly, this chapter’s purpose is to examine how parents negotiate their parenting experience, by analysing the meaning parents attribute to their children’s condition, the feelings they go through as well as the resources they use in order to cope with the challenges of their experience of parenting a child with developmental disability.

6.1. The meaning of parenting children with disabilities

Parenting a child with developmental disabilities is a unique, life-changing but also challenging experience. In this research parents’ narratives about their experience of raising their children with disabilities are not always shared but rather varied. For instance, for some parents parenting a child with disabilities is characterized with a positive, for others with a negative attribute and for some it is both. The analysis identified five basic themes in the meaning that parents attribute to parenting a child with disabilities: as a *burden*, as a *struggle*, as a *blessing*, as *a ‘no-different’ parenting experience* but also as *parents’ lost expectations*.

6.1.1. As a burden

For some parents, their child with developmental disabilities is represented by them as a burden. Parenting a child with disabilities means a permanent dependence on the parent, for now and in the future. The burden of dependence seems to have been absorbed by the parent and is reflected in their thoughts and narratives. Most parents initially mention practical day-to-day issues such as the child's lack of self-care skills but they end up living with an endless worry about the future. For instance, this mother describes the obligatory overall nurture of her daughter, which creates a relationship of constant dependence between them:

ED. What would you do? If you could, what would you do?
(…)

I. Basically, I would prefer if Nayia did not depend on me.
ED. Mhm.
I. But I'm also attached to Nayia whenever I leave her with anyone else, because I want others to pay attention to her. For example, if I let others take Nayia to the beach. Or if they go biking together. Or take her to the playground. But that person does not exist. So, I attach myself to Nayia. Elias, for example, talks about taking her to his mom's house. Umm I don't like that. There's nothing for Nayia to do there.
ED. Yes, I understand.
I. Okay? Elias won't take her to the beach, he won't take her to the playground, he won't take her, there is no one I can leave Nayia with.
ED. No one to trust.
I. Yes, exactly. And also, someone who would do things that Nayia likes, going for a walk, something that will make Nayia have a good time. That person does not exist. (…) It's really difficult for me, Eleni. Sometimes it's so difficult that … it suffocates me. It is extremely difficult for me.
Irene, mother of an 11-year-old child diagnosed with cerebral palsy

Irene describes in plain words the absolute dependence of the child on her, which is experienced as a great, suffocating burden. The child's everyday needs generate this dependence, and the mother feels "stuck" by trying to satisfy those needs. However, this endless effort makes her feel the need for rest, which she prefers to sacrifice, as in case of involving anybody else in her daughter's parenting – even her father – the child will not do anything useful, pleasant or educational. In front of this dilemma, the mother choses to bear the burden.

Another example comes from the following extract, where the mother focuses on the non-stop engagement with her son:

E. And then you realize … that your life now only consists of school, therapies, things of that nature. You had no life. Every day is the same, from Monday to Sunday.
ED. Yes. What you say is really interesting (…) It's like you are completely focused on your child.
E. Yes. You transition from being at work to being a housekeeper. What they call a 'professional housekeeper'.
ED. Okay.

E. Umm … (unintelligible) it was, was … so that's how it should have been done. So … if you didn't have the strength, what would happen? You just woke up, and got dressed to take your child. You know, you saw yourself … okay (…) Umm and it was emotionally draining. Are all the days the same? Summer arrived, Summer left, Winter arrived, Winter left, every day was the same.
ED. Mhm.
E. When you go to work, you are in a different environment, you talk about other things … Umm … and then when you return home, you face the issues. And the weekend is something different. Even with a child with a disability, I would be home in my pajamas for example. I wouldn't be running around. For me, every day was the same.
ED. You attribute this to the fact that you stopped working though. (…)
E. Umm I think the main issue was that the responsibility was entirely on me (…) Yes. It was impossible, there was no one to take my son to school, even once. There was no one I could tell "I don't want to take him to school today". "I'm tired". Ask his dad to take him. No one would do that. Everything (emphasized)! Everything! Everything! School. I would have to take him. Pick him up. Therapies. I would have to take him. I had to do everything. All the time.

Elena, mother of a 10-year-old child diagnosed with autism

This large «load», according to Elena, is monotonous and the same during the whole year, giving the representation of a rigid commitment and a flat lifetime. Continuously repeating how all her days feel the same, she highlights the impact this situation has on her, thus feeling that she "has no life". All parenting responsibilities are up to her, without replacement, every single day. The mother also emphasizes on the transition from a working to a non-working status, losing her personal life because "that's how it had to be." Employment involves changing the parent's setting, so that she can better cope with the home problems while creating a distinction of the everyday life from the weekend. Elena suggests that the working parent, unlike her, is taking a "breather". Another interesting point is that she observes herself experiencing this transition (*You know, you saw yourself),* being a working mother herself in the past and making some inevitable comparison with her previous employed self. The way this situation was described emerged mother's feeling on her parenting role as overwhelming, as mentally and emotionally demanding.

Both previous excerpts highlight the mothers' physical and mental load and the labour needed for their children's everyday life (i.e. school) or leisure activities. This seems to pile up, building an unbearable everyday experience, as the fatigue is permanent. This load is nonstop, for all the years of the child's life – not for a certain period such as in infancy, as

Marina states in a following narrative (*M. It's better when it's a newborn child)* – where there is no person to replace the parent, it is a life-long commitment to meeting the child's needs without replacement and without leave. Parents' words create an indication of losing their sense of self, since they are not living for their own self but living through and for their child.

Along with the child dependence, this father focuses on how his daughter's diagnosis affected his own life:

ED. What did Sophie's issue mean to you?
D. What did it mean? That I have a child who would always need me to be close to her, to look after her. That life as I knew it, was over. That I would have to quit my job and start another job. And that she would always need me to be with her.
ED. Yes.
D. So … I felt like my own life was over.
ED. So it was a huge commitment.
D. Of course, it is a huge commitment. Hehe (chuckle)
ED. Yes.
D. As I said, we quit everything and focused solely on Sophia.
ED. Okay, to tell you the truth, this sounds very … heavy, that 'my life is over'.
D. Well, it's certainly over.
ED. Yes. Has your perception changed somehow now? That is to say, do you perceive it somewhat differently now?
D. Well, look. We have a different routine now, we have accepted it, so we are trying to be happier. Somewhat. And the more we see her make progress, the better we feel. Because we are actually sacrificing our lives, but our child makes progress.
Demetris, father of an 11-year-old child diagnosed with autism

Demetris, here, intensely illustrates his daughter's dependence as the end of his life, the end of the life he lived until then. The burden of the lifelong commitment is experienced as an ending, as a loss. The loss presented by the father is obviously symbolic but is also real, as he left individual and personal goals (work) or choices (personal, social life) to devote himself entirely to meeting the needs of his daughter. All other parts of his life were abandoned forever. His life is sacrificed for his child's life, with no choice or alternative. This creates a sense of dead end, with no exit, feeling trapped from their own child's dependence.

Completing the reasoning of Demetris, his wife Eleftheria in another narrative describes their child's dependence as a form of absolute integration, an obligatory – not pleasant – merge, where child and parent are indistinguishable (*… she will always be by my side, we will stay together. Umm … as one, we are inseparable … it is*). In fact, she uses the word "life-long" (meaning equals a life) which in Greek language is used in prison life sentences, giving a sense of permanent "imprisonment" to the situation she has found herself in (*a life-long situation*. *An unpleasant situation*). Both parents here share the same sense of unwanted commitment, like the child's dependence takes away the parent's independence.

Other parents, like Marina, focus on the child's permanent dependence, which requires from parents to sacrifice their independence (*M. Umm it is a non-stop, constant struggle. Having a child like this. For example: in our home, he can't shower on his own, and as a parent, you will never feel independent. You know? He will always rely on you*). This dependence tremendously impacts on the parents' personal, family but also their social life.

6.1.2. As a struggle

Parents represent their experience with their children with disabilities as a constant struggle. The condition of dependence, combined with the increased children's needs due to their disabilities, imply a continuous effort on the part of the parents. This effort was evident in their words, talking about struggle and battle in their daily parenting experience.

The mother in the following extract describes quite vividly what the fight of parenting her son with autism involves:

T. And … I've found an entirely new world. I've met remarkable people, remarkable parents, who fight. I've met occupational therapists, speech therapists, people who I didn't even know before, who do an excellent job. Umm … secondly, it makes me stronger as a person. I mean umm that I have to fight, to take life into my own hands so I can be a better mother for my baby. (…) *And to be honest, a lot of people say that it's a blessing. It's not a blessing, heh (smiles) It's a battle.*
ED. Yes, it's a battle. It's a battle.

T. And … I don't … umm maybe it will be a blessing when I accept it. But for me, it is not a blessing at the moment. It's not a blessing. Hehe (faint smile).
ED. What do you think you are fighting against, Theodora?
T. Well, I will fight against everything … Eleni. I will fight. Against the school, against society, against every clueless person, I don't, I don't. umm I will protect my child. It's not easy.
ED. Yes, yes, yes, yes.
T. And against myself. For my child to be able to live independently. (…) But now with Petros, it is a huge battle, for him to, to learn, umm simple things, for example. Or to accept them, it is a change, for him to learn something. It's a battle.

Theodora, mother of a 6-year-old child diagnosed with autism

Theodora experiences her child's disability as an everyday struggle that must be fought. Everyday experience involves a continuous and intensive struggle, a multiplied effort compared to the usual effort needed by other parents. This effort surpasses oneself, it is an effort towards every direction, even a struggle towards oneself. This struggle may possibly prove fruitful for the mother's self-development as a person and as a mother (*it makes me stronger as a person; I have to fight, to take life into my own hands so I can be a better mother*) but at present is an absolute necessity for the fulfilment of the child's needs. It is worth mentioning that the struggle described by the mother is present and future, as it also concerns a future goal for the mother. Interestingly enough, this struggle is understood by the mother as a shared phenomenon, concerning all parents of children with disabilities and not only the mother interviewed.

The necessary devotion to every little detail is an element that many parents emphasize, which ends up requiring a great effort for every obvious need of the child. The following narrative exemplifies this difficult struggle:

D. The most important thing was figuring out what we have, what we need, and what we must do. You had to take it all into consideration before making a choice … For example, finding the private nursery school my kid went to at the age of around three years old. I had to do a whole … umm … I mean at first, I was worried, concerned. "What are we going to do since the child has difficulty eating? Um in which nursery school will they look after the kid properly for example?"
ED. Eating. Mhm.

D. I mean, I wanted to discuss this with other people, hear their opinion, take things into consideration, to … think, for example. Um it's not only about the end result. In the end, I talked to him for example and said "let's go take a look at this nursery school". It's not, that was just the result! (…) I went through so much trouble to reach this decision and … hehe (chuckle).

Demetra, mother of a 6-year-old child diagnosed with Alpha syndrome[20]

Demetra describes in a very characteristic way the procedure of looking for a nursery school for her daughter with a rare syndrome when she was a toddler. The worry she experienced is noticeable by the way she is expressed, using three verbs in a row. Every daily effort, every small or big decision (i.e. like school selection) turns into a time consuming and laborious process, where the parent is required to go through various stages of struggle. This process is exhausting and concerns every developmental stage of the child, giving the feeling of a staggered continuous effort. This particular extract also implies a sense of loneliness that the mother – also a single mother – may have experienced, since she went through the search process alone.

Entering the education system is a source of stress for parents of children with disabilities, which is associated with a large part of the struggle. Antonia in the next excerpt describes the entrance of her son into the pre-primary class:

A. Because you read so much, how you view it, I feel like … I experience it, he has difficulties in every area. And you have a really (emphasized) big battle, it is a huge battle now in preschool, for example. So, imagine how big of a battle it's going to be when he is in primary school, in secondary school, you don't have the support you need. Whereas if he was a typical child, just like the rest, his course would at least be predetermined.
ED. Yes, yes, yes.
A. But our course is unknown.

Antonia, mother of a 6-year-old child diagnosed with autism

Another factor that determines parents' struggle is the fear of the unknown. The mother feels that she is fighting something unknown, creating an additional condition of uncertainty and anxiety. On the one hand, she emphasizes the degree of the present as well as the future effort, additionally considering though the lack of support. On the other hand,

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[20] Alpha syndrome is a pseudonym of a rare syndrome.

she compares her struggle to the course of a child with typical development – as a mother of two children, with one of them in the spectrum, she also experiences parenting a child with typical development – confirming that parents of children with typical development don't experience the same fear and anxiety.

A description shared by certain parents is metaphorically presenting this effort as ascending a mountain, representing adequately the size of the struggle. The following extract comes from a group discussion of mothers of children with several developmental disabilities:

An. Yes, I also feel sad sometimes, and I have … for God's sake, there are times when you lose hope and you say "Jesus Christ, this is an uphill battle".
At. Yes, sometimes it happens, yes.
An. And then you say "okay, this is an uphill battle".
At. It's a hill. Okay, I will climb on top.
An. Come on. Yes.
At. And after you reach the top, you will go downhill.
An. Yes.
(laughter)
At. And again. That's the way it is, yes.

Anastasia & Athina (group discussion)

What is interesting from this group discussion extract is that one parent completes the other's words, creating a single narrative. The extract here demonstrates that the parents' experience of raising their children with disabilities is a shared one, is quite familiar and seems to be experienced as a circular process: they climb up the mountain, experiencing the struggle, but then they go down. The downhill here might be related to some form of hope, as if they expect it to go down, making them feel relieved.

A common point shared by several parents in these extracts is that despite the extent of the struggle or the burden, most parents of this study do not seem to resign or quit but to engage further in this perceived battle. Parents fight back and continue fighting (*D. … therefore we try to be happier; T. … I have to fight; At. this is an uphill battle. I will climb on top*). I will discuss that in detail in chapter 6.4.2.

6.1.3. As a blessing

Parenting a child with autism or intellectual disability is also described as a blessing by some parents. The struggle is still there, but it is approached as a chance for parents to experience a kind of transcendence. In the following extract, the mother outlines her effort raising her son to conclude that this effort is a blessing:

E. It's the difficulty, it's, I will tell you how I view this difficulty. Not as a curse. Do you know how I view this difficulty? It really is a challenge. This difficulty is a huge challenge. Look. We have, every difficult situation we go through makes us learn. We become better. And Stephanos' difficulty, autism's difficulty, umm there are times that … um you may reach your limits and cry, and say "I can't", and say "I can't stand this anymore". Umm but you get to the point of seeing that, the essence of life. Eleni, I don't bother with things that used to bother me. (…) Umm nothing affects me anymore. Nothing affects me. I used to be affected by everything, now nothing affects me. Only my kids.
ED. Yes, yes, yes, yes.
E. That's why I'm telling you. It's a blessing!
ED. Heh (smiles)
E. A huge blessing.

Elena, mother of a 10-year-old child diagnosed with autism

Parenting a child with autism is presented as a trial, nevertheless the mother ultimately feels blessed to have experienced it. Elena describes her experience as an opportunity to reflect and appreciate what she already has, namely her child with autism. This trial she goes through validates even more the effort: it is hard to raise a child with autism; however, it is an assessment, through which the parent goes and learns, evolves and becomes a better person. Going through this process, the parent becomes able to identify what is important in life, developing a kind of "filter" to distinguish the important from the unimportant. And she progressively learns to consciously deal with what has value in life, making her parenting a different and finally an exceptional experience. The mother illuminates a passage, a transition to a different, more conscious and ultimately more meaningful way of life. This transition is the outcome of the struggle she experienced through parenting her child with autism.

The realization that the experience of raising a child with disability is a blessing is expressed by Marina as well:

M. Umm but okay, it's something that you must … I am now at a point… We must feel that this is a blessing in our lives. Because … (her eyes water) I am getting emotional again. (…) First of all, these kids make you a better person. I mean … umm can I tell you something? I grew up in a really kind family so we didn't have such issues. We weren't selfish people. I haven't noticed that much of a difference in my personality. I am just the way I used to be. But for many other people, this has changed their personality. They used to look at life in a different way. You know? Their life, for example, was based on consumerism.
ED. Yes.
M. Their life consisted only of traveling, it was only (…) I have won … (short pause) I believe I have fully experienced what life means, what battling means, what sacrifice means. And I believe my faith has been reinforced. And that it is a blessing for someone to experience all this in their life. I mean, I wouldn't want to be a self-centered person, a proud person, looking only after myself, caring about the clothes I will wear, about the clubs I will go to.
ED. I see.
M. For the… Umm I now feel like I've won, like I know what the meaning of life is. (…) They should know that they are blessed.
Marina, mother of a 9-year-old child diagnosed with developmental disabilities

Marina here presents her parenting experience as a blessing, giving her the opportunity for a higher level of self-development. She confirms – like Elena in the previous extract – that a change is taking place, a transition to a better and upgraded way of life, expelling the negative elements and gaining a level of self-development. The mother emphasizes on the creation of two opposite poles. On the one hand, there is the pole of having an egocentric lifestyle, full of ephemeral satisfaction and consumerism. On the other hand, there is the pole of the sacrifice, the struggle and the personal development. Parents of children with disabilities have the chance to experience the second pole, which allows them to understand the meaning of life. It is through struggle, therefore, that parents become better humans, learn the meaning of life and have been benefited by a form of self-development. It is worth noting, however, that Marina initially separates herself from the negative characteristics, as someone who does not need this change. Afterwards, however, she admits that she has changed and that she has benefited from the "blessing" of this experience.

It is interesting to underline that parents feel empowered through this process. This special experience makes Elena feel shielded (*E. … Nothing affects me*) and possibly stronger. Marina feels her faith has grown stronger as a result of her parenting experience (*M. … I have felt 100% what life means … and I believe faith strengthening).*

6.1.4. As a 'no-different' parenting experience

All above narratives point out something exceptional about parenting a child with developmental disabilities, with a negative or a positive sign. Parents' experience of raising a child with disability is also represented – or rather negotiated – as a variation of the parenting experience. Take the mother in the following extract for example, talking about taking care of her son:

K. I will face whatever may await for me when the time comes. That's what we live by, that we have a child who is different, who needs a little more care than other newborns, every baby needs care, he needs a little bit more.
ED. More.
K. Yes. I was feeding him, for example, because he was unable to drink his milk, I would give him …
ED. With a spoon.
K. Not with a spoon …
ED. With a syringe.
K. Yes.

Katerina, mother of an 11-year-old child diagnosed with Alpha syndrome[21]

Katerina describes her son's rearing and nurture as an alternative condition, as another parenting experience. The mother raises a child who needs more care than other children. This takes some extra effort, yet it is represented as a varied – not negative – parenting experience. Specifically, she explains how she used to take care of him when he was an infant. This is about a different child, in need for a different kind of care, a little bit more care actually. But still, she had a child to take care of. Therefore, this is about a no-different parenting experience. This consideration reveals a kind of 'normalization' from the mother's view, representing disability as a variation of human diversity.

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[21] Alpha syndrome is a pseudonym of a rare syndrome.

In a similar manner, the mother in the next excerpt emphasizes on the different way of life:

E. (…) Umm you look at things in a different way now. You look at the world in a different way. Everyone (emphasized) faces a difficulty at home. Everyone … (unintelligible) faces a difficult situation at home, different difficulties. Umm … for us it was, if, if you stop thinking about it as a difficulty, you look at it as a different umm … as a different way of life, which is a good way of life! But it's also bad. It is a different way, a good way of life. Big deal, why should we all be the same? We have different things to go through.
ED. Yes.
E. You reconsider a lot of things. One of the things you reconsider is this. Different meanings. Different joys! (…) It's not the end of the world. It's, it is cut, umm your life gets bleaker, because you don't know about this, this is new, it's something really (emphasized) different. You must alter your life a lot.
ED. Yes.
E. So it's not the end. It feels as if a black curtain falls. And now you're trying to put that black curtain aside. To see what you can detect in the dark. (...) And you slowly move on. And you alter your way of life. It's not (emphasized), I don't accept it. I don't accept it as being the end of the world. The end of the world would be umm facing an illness, something you can't be saved from. (…) An illness you can't, can't cure. I don't accept it as being the end of the world. I don't accept it.

Elena, mother of a 10-year-old child diagnosed with autism

Elena focuses on this different quality of her experience, stressing out her positive reflection on that. She describes it as a different parenting experience and a different way of life. Throughout this different course of life, both worries but also joys are different. According to her, it depends on how this situation is conceptualized, emphasizing the perspective from where one can approach this. She chooses to use the diversity "lens". To support her argument, she raises the question of the need for similarity, considering the dilemma of difference versus similarity. However, despite the different perspective the mother tries to point out, her narrative also reveals a dark aspect of her experience, expressed by the phrase "black curtain". She attributes this dark aspect to the factor of the unknown, as a completely new and unknown experience. Besides, she recognizes a critical point, where her life was sharply darkened, after which she tries to make sense of and normalize this change. Consequently, her experience is not simply different, there is a dark aspect of this experience against of which she conceptualizes her experience as different.

The mother in the next extract uses a symbolic dialogue to represent her child’s autism as one among the many issues encountered in every family:

E. When someone asks a parent, “what's the matter with your baby?”, the reply is “we have autism, what do you have?”
I. Hahaha! (laughs)
M. Hehe (chuckle).
E. And I’ve used this reply, and whoever asks me that, I will reply the same way. Because … “yes, that’s what we have in our life. What do you have?” As if to say … we all have something to deal with. I mean …
An. As a side note, only a few people are not on the spectrum
E. Yes. Even the best families have their own problems.

Evangelia, Irene, Marina, Anastasia (group discussion)

During this group discussion, Evangelia tries to normalize the experience of raising a child with autism, humorously, by suggesting that there are problems in all families, with hers being no exception. Autism is, thus, represented as something trivial, equal to other problems. This trivialization is also sustained by the interlocutor who supports that not having autism is rare.

The last two narratives emphasize on problems as a general horizontal phenomenon, as all families have to face a small or a big problem, meaning they also belong to the group of "normal" families. This view serves a dual purpose. On the one hand, the child’s diversity is openly discussed, not followed by negative or overemotional descriptions. On the other hand, there is a focus – even by adopting a reactive behavior like Evangelia does – on the variation of problems and, therefore, of their parenting experience, reestablishing a sense of normalcy. In all parental accounts of this chapter, there is a clear representation of parenting as being no-different from parenting a child with typical development. This may be seen as an effort to normalize their experience (further discussed in chapter 6.4.2). Placing their child’s disability in the broader context of all problems seems to allow parents to negotiate their experience and find an active way of making sense of it through a less painful process.

6.1.5. Parents’ lost expectations

Several parents express the frustration and disappointment they felt regarding their lost expectations of having a healthy and sufficiently functioning child. Or as Landsman (1998, p. 76) states, they experience ‘the trauma of dashed expectations’.

In the following excerpt, a father of two, the older of which is a boy with autism, describes how he realized that what he was dreamed of his family and his relationship with his firstborn son will not – possibly never – come true:

A. Okay. Umm … I don’t know if there is a positive or a negative aspect. Because a lot of things are happening. You have the good, you have the negatives, you have the bad, and good days, and bad days, mediocre days. The … worst, so to speak, is that you don't have what you dreamed of, the dream family, to say “yes, we will do this, we will go there”. You know, it will do … I mean … When Philippos was a newborn, I held him in my arms, for example, and I told him “hey kiddo, (claps hands) when are we going to talk?” Okay? “When will we talk to each other?” (smiles) I don’t know, you have this … this … you know, this anxiety … how this person will be shaped, his personality, what you will talk about with this kid, what you will do, you know? And he was a newborn, and I told him “when are we going to talk, buddy?” Okay? And yet, Philippos is who he is, and he was late to start speaking. And maybe having these father-son talks, abstract or similar talks, will never happen.
ED. Yes.
A. Okay? Have you accepted it? I have accepted it. And there was a time when I told myself “hmm, you spoke too quickly, buddy”.
ED. Hehe (chuckle)
A. “You spoke too quickly”.

Alexandros, father of a 6-year-old child diagnosed with autism

Alexandros here expresses specific expectations about his ‘dream family’ and how, in such a family, he would communicate with his son. However, what he finally got is not what he expected and he realizes that he must give up the dream of the ideal family and the father-son anticipated interaction. From his narrative it is obvious that autism and the subsequent dashed expectations because of autism are fundamentally a negative issue. As the father puts it here, it is as if autism took away from his son part or all of his personality, the part that allows the emotional and intellectual communication in theoretical context with others. And along with his communication skills, it destroyed the father's expectations about communicating with him and living the ideal father and son relationship, a determining for him element of the ideal family.

The idea of taking away or losing one's child is also described by the mother in the following narrative:

D. (…) The worst thing in our case is that … umm from the beginning, you feel like … you lose your child and that you can't have some things. (…)
ED. (…) What do you mean by that?
D. Umm I don't know how to say this, but … it's as if someone sucked (emphasized) some things out of my child, removed them from her. And now my kid doesn't have these. These things. (…) That something, something has been lost. Forever (emphasized). Something that rightly belonged to my child has been lost. And she doesn't have it.
ED. Okay. Mmm, mmm.
D. Aside from that, the specific syndrome is accompanied by some facial characteristics, but I don't think about it anymore, but to tell you the truth, in the beginning, I looked at her face and … I was wondering, for example, how Natasha would be if she didn't have this syndrome. How would her face really look like?
ED. Mmm.
D. If she didn't have this syndrome. Would she look like me? Because usually, children with this syndrome don't look like any of their parents, because they have the syndrome's characteristics (…)
ED. Ah okay. Mmm, hmm.
D. So basically, at first you feel like … you don't see your child. But now, I don't think about it … as … much … it used to cross my mind, would Natasha look like me, for example?
Demetra, mother of a 6-year-old child diagnosed with Alpha syndrome[22]

Demetra represents powerfully the feeling of losing a part of her child, reflecting on the subtraction of essentially defining characteristics of her child. Specifically, she explains the removal of the good elements of her child or the elements that give meaning and personality to her child, elements which rightfully belonged to her daughter. Additionally, the expectation that the child would look like the parents, as a continuation of them, is very

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[22] Alpha syndrome is a pseudonym of a rare syndrome.

well represented here. The representation of the “normal” child is also emphasized, as the mother forms a picture where someone removed her child's ‘normal’ personality traits and added the syndrome's traits. The removed elements are apparently related to the expectations she had as a mother for her child. She concludes how the removal of these traits works in such a way that she doesn't recognize her child – basically affirming that you "don’t see your child", as the continuation of the parent, in that person you're trying to care for – describing a kind of depersonalization that she feels in relation to her child.

What is interesting in the two last extracts, is that the parents describe what they experience as if they mentally separate the child from their diagnosis.

What the child misses as a ‘non-typically developed’ child is a common way of thinking among parents of children with disabilities. Take the mother in the following extract for example:

E. Why should that committee know, five people, clueless, where you go to state your case apologize just so they will give you the government benefits you are entitled to receive. And you take your child there, when it’s crystal clear what your child has. And that, it is a given that we would prefer to have a typical child, and you could keep your benefits and whatever … you are obliged to give. And that this whole thing is really emotionally draining.
(…)
ED. How do you feel about Sophia having autism? You, as Eleftheria, for example, you are a separate person. How do you feel?
E. Okay, I feel sorry. I mainly feel sorry for her. That’s why. Umm somewhat I … I keep thinking that now, at her age, she would meet with a friend, she would have English classes, she would do activities other children do.
ED. Yes. You’re thinking about what your child is missing out on. And … maybe the things you’re missing out on as well.
E. Mmm yes. Yes, exactly that. (…) Yes. And what she misses out on. That … umm she will never be able to be a mum, she won’t have … that’s all.

Eleftheria, mother of an 11-year-old child diagnosed with autism

Eleftheria – while talking about the reassessment procedure regarding her child’s disability benefit with resentment – openly expresses her expectation, which she also shares with her husband, for a ‘typically developed’ child. The mother would certainly prefer not to have to address this assessment committee, expressing, in fact, her willingness to “sacrifice” any benefit to satisfy her expectation for a child without disability.

Right then, not coincidentally I suggest, the mother refers to what her child loses as a ‘non-typically developed’ child, listing specific things that a child with typical development is expected to have or live. Her daughter, as a person with disabilities, loses those things, both in the present and in the future. The mother clearly represents in what her daughter "loses" her own lost expectations of what her normal daughter would be like. This realization brings disappointment and feelings of sadness to the mother, feelings that refer to the daughter but also possibly to herself as a mother too.

Lost expectations are similarly illustrated in the next narrative. But this time, they are contextualized in a different way:

A. Okay, certainly … if, I think (faint smile) I believe that nobody would … if they could say that … there was no disability, I don't think there's anyone who would say “yes, I want a disability”.
ED. Yes.
A. I wouldn’t have wanted to have the disability. But it’s something you learn to live with. I mean, umm … you have a child with a disability, before you give birth, you have some dreams, and so on. After you give birth, you change those dreams. And then you see that you can make new dreams gradually, based on how the child progresses. Okay, umm … *I don’t have a negative opinion on disability. I believe that since he, who has the disability, is happy (short pause), okay.*
ED. Okay.
A. He is healthy and happy, everything else … will come in time.

Andriana, mother of an 8-year-old child diagnosed with Down syndrome

Andriana in this narrative suggests that everyone would not choose disability if they had a choice. However, according to her, the disability condition is something you have to learn to live with. The anticipated expectations for the child to be born are different in the case of a new born child with disabilities. Specifically, the mother underlines that those expectations should respond to the child's rhythm – which is slower in case of disability – and should be done gradually so as there is a significant possibility for them to be fruitful.

Unlike other parents whose narratives are discussed above, Andriana does not seem to express suffering or trauma over her lost expectations. Her narration evokes a sense of development – "post-traumatic" according to the literature (Joseph et al, 2006) – since her lost expectations are just changing course, are differentiated, following a different "rhythm", more appropriate for her son with disabilities. Additionally, the mother seems to place the importance on happiness and health and devaluing the importance of disability. By placing a criterion outside disability and functionality, happiness, she expresses an open view of 'normalization' of disability. As long as the person is happy – obviously implying her son – it doesn't matter if they have any disability or not. The differences in the way parents experience these expectations also seem to be due to the fact that they might be at a different stage of acceptance of their children's disability. Besides, it could also be related to the parents' personality traits, regarding for example their resilience or adaptive characteristics, their confidence level or their anxiety traits.

6.1.6. Summary

The meaning of parenting children with developmental disabilities varies for most parents. Some parents describe their experience as a draining and heavy burden, impacting directly their way of life. Other parents emphasize on the constant struggle, mainly due to the child's dependence. Parenting a child with disability is also described as a blessing by some parents, as an opportunity for self-development. Other parents represent parenting a child with disability as another parenting experience, in a broader attempt to normalize their experience. Lastly, some parents discuss their frustration stemming from their lost expectations of having a healthy child.

6.2. The feelings of parenting children with disabilities

Parenting a child with autism or intellectual disability is full of intense feelings. Some recurrent themes regarding parents' feelings emerged. The parents seem to experience *anger*, *anxiety*, *fatigue* and *pain* concerning their experience of parenting children with developmental disabilities. *Fear* and *uncertainty* are as well between the feelings usually mentioned by parents. However, the parents also discuss about positive feelings, such as *satisfaction* and *hope*. Additionally, they discussed about their *feelings as a motivation for action*.

6.2.1. Anger and questioning ‘why’

Anger emerged very often in the parents' narratives. Feelings of anger permeated the parenting experience, sometimes with an obvious direction and sometimes more pervasive, towards a superior power, namely God (religious faith is discussed in detail in chapter 6.3.2.). Anger was often accompanied by questioning why and a sense of injustice.

Georgia, in the following extract focuses on the feeling of anger:

G. At first, I felt angry. Very angry. I mean, why? Umm I used to really believe in God (smiles), I lost my faith. Well, I lost it because I kept saying, “what have I asked?” … I remember my first baby, it took me 8 years to have one, I had difficulty having a baby. And … I just asked for a baby. And you sent me one and a half (awkward laughter). And I had it … I lost my faith, I lost … why? I asked you for a baby, why would you send me one and a half, for example? After 8 years, I had my first baby, who was perfectly healthy. I didn’t ask for a second one. The second one … I had the first one after I went through therapies, I had the second one naturally, why (awkward laughter)? This … anger. Pain. Anger…like this.
(…) I still feel angry, yes.
ED. You still feel angry.
G. Yes. Anger, I told you, towards … towards God, let’s say? I don’t know if God exists anymore. I used to believe. I lost my faith… I don’t think that there’s a God anymore, I don’t know, I don’t believe God exists. And…
ED. Mhm.
G. If it’s not towards God, let’s say towards the universe. I feel anger. Not only for me, for all families. Umm they once said … a priest said that God isn't perfect, and that we should look at how perfect the world is. Well, no (laughter) it’s not perfect (laughter). Someone lied to me, I feel angry. Why did he lie to me (laughter)?

Georgia, mother of a 5-year-old child diagnosed with autism

The mother here describes her feelings of anger in an intense way, directly addressing her anger towards God. Her narrative suggests feelings of betrayal, as she was given something else instead of what she asked for. Her words produce a cry of protest for not being fair to her. She expresses very vividly her anger towards God. This betrayal – speaking openly about lying – made her lose her faith, so she questions God’s existence, but also God’s quality and then turns to other superior forces, like the universe forces. The anger she feels is generalized, as if she stands for all families with children with autism.

Her anger is also indirectly related to the child's conceptualization as non-normal. Specifically, the mother represents the child with disabilities as a half child, giving a very powerful image of the meaning she has constructed about her child. Thus, her anger has a strong background and is connected to her child's representation as lacking, as deficient, as half a child. It is obvious that she is anguished of why she was not given a normal but a defective child, which causes her anger.

Questioning why, as above, is also a pattern shared by many parents. The father in the following extract exemplifies this questioning:

M. On many occasions, okay, you feel disappointed. But it's something you say to yourself (emphasized). "Why me?" That's what you say.
ED. Ah. Aha.
M. Okay? That's what I say. Okay? Here and there. But I won't tell that to anyone else … hehe (chuckle) … that easily. Besides Christina, for example. Okay?

Marcos, father of a 7-year-old child diagnosed with autism

Questioning why does this happen to him reflects a generalized disappointment and complaint, a kind of grievance. He chooses not to share beyond the family, indicating that this is an individual or a family issue, and not a social one. Therefore, he considers that this kind of feelings are not legitimate in the social context and prefers to keep them within the family. The social context (discussed in detail in chapter 5.3.) appears to play an important role in how parents express and handle their feelings about their children's condition.

In this process of questioning, parents feel a general sense of injustice, which is very clearly illustrated in the next extract:

D. The way I explain it is that life is unfair, the world is unfair. Well, unfair things happen. (…) I mean, everyth… pff … unfairness, you see unfairness everywhere. And I feel a lot of anger about this issue.
ED. Mmm.

D. Not only for Natasha's issue. Okay, Natasha's issue becomes more severe, I mean this is about my child (voice breaks, sounds like she's crying) for example. Let's just say that even before Natasha was born, umm I mean, I saw these things … (…)
ED. (…) Where do you think this unfairness comes from?
D. I don't know where it comes from. The only thing I know is that I am very angry with … with anything that can be thought of as God. Umm … I really don't know if I believe that God exists anymore.
ED. Mmm. Whereas you believed before? Did you have faith for…?
D. No, I wasn't, it wasn't that … It wasn't like I had faith. I was not pious, let's say. Umm … it's just that now, for any god that may exist, umm … I am, I have infinite anger inside of me, for anything that may exist. (…) But still, but still that doesn't mean that I believe (emphasized) that, heh (smiles), let's say it … It just was … it was some kind of reconciliation. That I felt strong for example. Whereas I was a wreck.

Demetra, mother of a 6-year-old child diagnosed with Alpha syndrome[23]

Demetra conveys her daughter's condition to the fact that there is injustice in that world, which makes her feel angry. This anger is again generalised, regarding not only parents but general aspects of life. Anger seems to intensify here, talking about feeling crushed, with unlimited anger. The anger toward God might also concern the parents' lost expectations of having a healthy child, namely what they were expecting and what God finally gave them. This anger makes the mother but also other parents as well doubt about their faith.

The doubt of faith is a recurring element, shared by many parents. It seems that the child's diagnosis is a defining rupture, a process of change, which – according to Symbolic Resources Theory (Zittoun, 2006) – is followed by transitions, in which people question their previous interpretation, how they understood certain issues and explore the construction of new meaning (meaning-making). Therefore, this was a stimulus for the mother to renegotiate her existing faith and possibly construct new meaning about the usefulness of faith for her regarding her daughter's issue.

Another interesting point is a contradiction described by the mother: although she doubts the existence of God, yet she is very angry towards God. This has more to do with the mother's need to deposit somewhere her anger, than with her recognition or doubt of the existence of God. Therefore, the mother's current feelings prevail her previous beliefs and values.

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[23] Alpha syndrome is a pseudonym of a rare syndrome.

6.2.2. Anxiety and fatigue

Parents experience an elevated level of tiredness, which is obvious throughout their words, as Marina exemplifies:

M. No. Eleni, they don't even understand that there are nights when you, for example, I went to work without any sleep. Do you know what it means for this to happen for months? People were talking to me and I couldn't understand what they were saying. In the end they even said that … that I was not a good employee, for example. No one thought "I wonder what this person goes through at home for her to come to work sleepless, with puffy, red eyes", "I tell her to do something three times, for example, and she forgets". Is it because we are dumb? Thank God, I also got a Master's degree. While having Maria.
ED. Yes, yes, yes, yes.
M. I finished it last year, when Maria was 8 years old.
Marina, mother of a 9-year-old child diagnosed with developmental disabilities

Marina represents the picture of lasting exhaustion due to sleeplessness. The level of such overtiredness would be expected in case of an urgent situation. The mother states how much physically exhausted she was feeling, with an obvious impact on her cognitive and bodily functions, a fatigue that was not understood by others. However, the practice of not giving up comes back here, as the parent did not give up on personal goals, namely achieving a postgraduate degree. We can also notice here the mother's need for recognition: by emphasizing the success on her academic goal, which presumes a level of skills, she attributes the cognitive decline exclusively to the fatigue she was experiencing due to her daughter's additional care needs.

The level of fatigue is also highlighted in the next excerpt, focusing on the parent's continuous state of tiredness:

A. Yes. Because this battle is tiring, I am tired. I've lost myself.
ED. This battle, what does it entail? What does it consist of?

A. The battle is for Philippos to become functional, happy, to be accepted, to be able to, to participate somewhere, there is a huge battle that I had to go through behind the scenes. For him to become who he is.
ED. Which is going to, to therapies …
A. Yes. Yes. Therapies, the time I spend with him. For him to be able talk, to be able play, to be able to do things by himself. (…) Yes. For example, it's summer now, July has gone by, it's umm… For example, I'm a teacher, I don't go to work at the moment (emphasized). I didn't get a chance to rest, I didn't get a chance to relax, my mind is full, because I took him to summer school. He couldn't adapt there, so I had to take him to a different one, a teacher told us some things, Philippos' own teacher was transferred elsewhere, I wrote 10 letters of complaint, I go to therapies. I didn't get a chance to relax.
ED. Yes.
A. I think that you can't even take a breath. You can never stop.
Antonia, mother of a 6-year-old child diagnosed with autism

Antonia lists every little or big battle that the struggle for her son involves in a specific period of time, concluding on how exhausting this struggle is. The mother sacrifices her regular holiday and leisure time. Additionally, it is emphasized that her fatigue involves physical tiredness as well as intellectually and emotional exhaustion. The mother is in a non-stop alert state, there is no room to relax, not even to breathe. This incessant physical and psychological exhaustion makes the mother feel that she has lost herself during this continuous process of trying.

The emotional tiredness might be more intense than the physical. This is something clearly illuminated by the next group discussion extract:

At. It is emotionally draining.
An. It is emotionally draining. Yes. There were times … Umm as many now, but in the past I would have something like a panic attack when I was around people, for example …
I. Yes. Umm …
An. I didn't know what to do. I started … hehe (smiles) … I reacted. It was as if I was the child, "I can't take this anymore!" What are we going to do here?
(…)
E. Of course you guys, we also have days where we can't function. That we can't stand it anymore. (…) Days when you come home at 7-8 at night, and you have no more energy (emphasized). You can't think of anything to … about the pictures, and so on.

(…)
An. Yes, I agree. But you panic in the end. In the end, this doesn't help you. I mean … Whether for good or for bad. I know that it’s not, I know that what you say is not unreasonable. But umm … you know, it’s that panic attack that feels like your heart will jump out of your chest.
At. Lies. (…)
E. I think that … I may get to live till I’m 50. And maybe that’s a stretch.
(everyone laughs)
M. God forbid (knocks on the chair she is sitting on). Don't say that.
I. Jesus …
E. Up to that age.
(everyone laughs)
An. You know, Evangelia is right. I mean … the … umm … so many times you feel so … the panic and the anxiety are so intense that you just say “Oh my God”. And then you say that you must (emphasized) live …
I. Yes, yes.
An. … until you’re certain that the … that your baby …
I. Is able to live without you.
An. … that your child is independent.
Athina, Anastasia, Irene, Evangelia, Maria (group discussion)

In this group discussion extract, mothers emphasize and agree on the mental load and the fluctuation of anxiety, which sometimes reaches the point of panic attacks. Anastasia focuses on the feeling of losing control and the tendency to react like a child, acting emotionally based and not rationally. They report specific intense symptoms they experience, acknowledging – by using humorous statements – that such levels of stress are harmful to their health. The absolute necessity of continuing the effort in order to ensure the required and appropriate support of the child emerges again here.

6.2.3. Pain, loneliness and trauma

A group of feelings experienced by parents concern feelings that usually accompany situations of depression or bereavement. Pain, sadness, feelings of loss, loneliness, self-worthlessness, trauma or parenting failure arise through parents’ words.

In the following excerpt, the father expresses the sorrow he experiences, not only through words but also with his body language, keeping a tight and taciturn attitude:

ED. (...) What do you feel when you hear about this subject?
D. Well, what would I feel? Heh (smiles). Because … I experience it every day, well how would I feel? How can I explain how I feel? An endless sadness.
ED. Mmm. Yes. What … what is this sadness related to?
D. Umm (sighs) it has to do with what the child has to go through daily. And what the child's family has to deal with as well.
ED. Mhm.
D. It is a great torment, for the family as well.
Demetris, father of an 11-year-old child diagnosed with autism

Demetris expresses his immense sorrow about the great suffering that his child and the family go through. The child's condition is represented as an everyday struggle, which generates a feeling of deep sadness and pain.

Other parents find it difficult to explain because they feel they will not be understood, as described in the next extract:

M. (…) One of the bigge…aside from the social exclusion, you get the feeling that others don't understand you. Sometimes, you want to cry for help, so to say. You feel like saying, "please understand what I'm going through".
Marina, mother of a 9-year-old child diagnosed with developmental disabilities

Marina explains in a few words that parenting a child with disability comes with a feeling of loneliness, as she feels misunderstood or not understood by others. Her solitude leads her to feel the need to express herself through a cry for help, not to be helped but to be understood.

Another feeling emerging from some parents' stories is self-worthlessness. The next excerpt gives a good example of this feeling:

I. Ha (sighs). Sometimes, umm people may tell me, umm "well done", and "you are something", I don't feel like I am great for raising Nayia. And people may say that.
(...)
ED. But you don't feel anything special?
I. Yes, that I am, and … but … Umm … I, I would like … I don't know.
ED. So what have you heard? What do people tell you? "Well done, you are…?"
I. Umm … "Well done for …" umm what did people happen to tell me. "You, you're a heroine", or something similar. (...) And they told me, "you are a saint for raising Nayia". Okay, I don't feel like that. Umm I certainly, have outbursts towards both Nayia and Nickie. But … yes, I understand that I should be patient, I should be strong. But I don't always manage to do so.
ED. Yes. It's not easy.
I. Yes. Well, Maria[24] probably feels sorry for me? And we're really good friends. (…) We're like sisters. She probably feels sorry for me.
ED. She's sorry for you, for what you're going through? Or does she feel sorry for you? That …
I. It's both. She feels sorry for both me and Nayia.
Irene, mother of an 11-year-old child diagnosed with cerebral palsy

Irene – mother of twin girls, one of which with cerebral palsy – seems to have a great difficulty to recognize her own effort but also her input concerning her child's achievements. Even when others praise her effort, she rejects it. Instead, she chooses to focus on her mistakes and what she should do. This feeling of self-worthlessness is also felt by the contact with this particular mother, where she projects a feeling of misery and despair. Her almost depressed presence is obvious by the way she thinks others, even close persons, see her, like feeling sorry for her.

Another kind of failure felt by parents has to do with the maternal role. Demetra, in the next extract, very vividly describes a kind of disparagement on her maternal role:

D. We always paid attention to the calories, they had us note down how many grams of food Natasha ate. I have them, the notepads my mum used. (…) So when, for me umm … it's traum, umm this whole food situation is traumatic for me. I, I am always worried about … whether she is doing well, whether her weight is normal, whether she eats

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[24] Friend of the participant mother, whom she mentioned during the interview.

enough. I mean, I am more worried than I need to be, because we have been dealing with this ever since she was an infant!
(…)
D. So umm … And because of the persistence of this person[25]*, I mean because he understands the psych, psychological aspects and … umm … I mean, he realizes the severity, how hurt (emphasized) I feel and that this wound is so deep inside of me that it prevents (emphasized) me, it paralyzes me, it prevents me from, from being free, to do, to look at my child freely. And behave freely. (…) umm it used to hurt me umm … and it still does. For example, umm I felt guilty that I could eat but my child was unable to, watching my child not being able to eat normally. I mean, eating, watching her not make specific moves, watching her not wanting to eat. I mean … umm I noticed it, I was hurt, I mean, I couldn't, I couldn't (emphasized)*
ED. Mmm.
D. I couldn't, I didn't want to, I wanted to avoid feeding her. (…) And I'm thankful for my mother. Because I was asking my mother to do it, umm honestly, I really couldn't. I couldn't face it.

Demetra, mother of a 6-year-old child diagnosed with Alpha syndrome[26]

The continuous worry experienced by the mother concerning the most essential aspect of her maternal role, that of the nurturing mother, has been imprinted as a trauma deeply inside her. Feeling helpless to meet her child's most basic need led her to feel guilty and experience a traumatic rather than a pleasant parenting experience. Thus, child's care, which often contains elements of satisfaction was experienced as a trauma, and consequently produced frustration and disparagement regarding the maternal role.

6.2.4. Uncertainty, insecurity and fear

Parenting a child with disability can evoke feelings of uncertainty, insecurity, fear, frustration and guilt. These feelings are usually associated by parents, creating a cluster of emotional experiences.

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[25] Referring to her child's developmental pediatrician.
[26] Alpha syndrome is a pseudonym of a rare syndrome.

The father in the next extract exemplifies this uncertainty, justifying the reasons of his feelings:

ED. Umm if I asked you to describe the fact that Alexandra has this syndrome in three words, what would you say?
Y. The first thing I would say was that umm … umm … there's uncertainty. Uncertainty about … umm how this will progress, uncertainty about what will happen. Umm the second one is that umm … there is difficulty to determine how we can handle this. Umm … that's all. And the third one is … there is hope that … things will go well.
ED. Hmm.
Y. I mean … in every … umm aspect, let's say, there is a different type of uncertainty, and a different … umm … how do you call it? An issue to solve. There was always something about how we would face this. (…) Yes. Umm … there wasn't umm … In general, it's not something for which you can make a choice and say "I will do this" or "I will do that". There's no option A or B, for example. There are small interventions here and there. I mean umm …
ED. Yes.
Y. I think that we have a deficiency, for example, in … in speech, so we will do some speech therapy. If I think we should strengthen that ability, we will do some exercises, for example.

Yiannis, father of a 4-year-old child diagnosed with nodular sclerosis

In the excerpt above, Yiannis describes the uncertainty he feels concerning how his daughter's disorder will develop. This uncertainty is related to the future and is dynamic, as it varies in each phase and does not concern a standard or an invariable issue. It is repeatedly transforming, so the parents' concern is constantly shifting to something different. This dynamic form of uncertainty produces an expected degree of difficulty and insecurity on how to manage the current situation. These elements – uncertainty and insecurity – seem to be decisive and partly restrictive on his parental role, where he is expected to provide security, besides the father feels uncertainty and insecurity. It seems like he is experiencing a constant strain on his parenting role. However, he does not fail to mention the hope he feels, that things will turn out well.

The parents' worry about the future is in many cases a constant concern, related to the uncertainty they experience, as represented in the quote below:

ED. Tell me three words that come to your mind. About this subject. About Maria having pervasive developmental disorder.
M. Yes. Umm (thinks) It's, it's … (short pause). In two words, I would say social exclusion (…) Yes. It is social exclusion. It's a fear of the future. Fear of the future. Umm it's hope. The hope, feeling that there's a hope that your child will get better. Umm and there's also uncertainty.
ED. Uncertainty.
M. Yes. You constantly feel an uncertainty inside of you, about what will happen, how it will progress, how it will …
ED. I see. Yes.
M. Not to mention the financial aspect of it. That is a huge issue as well. Because you want to offer everything to these children. And … umm … you have to leave something behind (…) For example, I would love to sign Maria up for music therapy sessions, but I am unable to do it. I mean, I want her to have a hobby. I send her to so many sessions of occupational therapy …
ED. To lessons.
M. …to lessons all the time. When she will be able to speak, she will tell me "I want to change, mum!"
Marina, mother of a 9-year-old child diagnosed with developmental disabilities

Marina points out three major sources of uncertainty: the social exclusion, the fear about the future and the financial factor. The uncertainty that the mother describes is mainly related to the child's unknown development – as Antonia discusses in a previous narrative (chapter 6.1.2.). Probably this form of uncertainty about the future creates an insecurity to parents regarding the efficiency in their parental role. Not coincidentally, Marina then discusses her concern about her child's lessons, the choice of which may not be enjoyed by the child herself. This implies a sense of guilt on the part of the mother, which may also be related to her feeling of effectiveness as a parent. Am I enough as a mother? Do I provide my child security? Those questions are hard to answer in the case of an uncertain future. In this excerpt, a separate mention is made about finance, another great source of uncertainty for the parents of children with developmental disabilities. The mother here reflects that she is not able to practically provide everything that her child needs. In the case of a child with disabilities, where what the child needs is more (more needs, more expenses, not always covered but paid services), the parent feels even more the impasse of this uncertainty.

What is interesting in the last two narratives is that both parents, along with uncertainty, they mention hope. It seems that uncertainty does not immobilize the parents, does not prevent them from hoping that things will turn out well in the future. Parents experience a kind of coexistence of two relatively opposing feelings: no matter how uncertain they feel, they don't give up hope.

However, for some other parents, uncertainty is more or less a generalised and continuing condition. Take the father in the following extract as example:

V. It's like someone saying "umm is this what you want?" "Yes." "It's in Limassol". Okay. If I don't have a car, I will try to go by taxi, or by bus, or by walking. But I will go to Limassol, I know where to go. Now when the question is "is this what you want?", the answer is "well, look around and you will find it". Well, where should I go? Should I start going towards Limassol? Towards Larnaca? Towards Nicosia? I mean … That is the …
ED. So with what you're telling me, you feel like you have no direction.
V. Yes. And I don't … aah … you clarified it very well with what you, that's what I wanted to say. That no doctor, neither the pediatrician, or the neurologist, or the geneticist, or anyone … they don't give you a direction … to tell you "this is the road in which we will be searching". (…) There isn't … umm a certainty that … at least you are headed in the right direction. To be sure that … I am going in the right direction, I am making the right effort. How, let's say … Yes, I take my baby to the institution for occupational therapy, speech therapy, and so on. Is this the right thing to do?
(…)
ED. Did you feel this uncertainty from the start, Vasilis? Or was it created after searching, learning and observing the situation?
V. Umm at the start I didn't feel it as much, because it was something unknown. By researching, researching, researching, you realize that … umm it is something unknown, because no one knows. It's not you who is … uneducated …
ED. Lacking. And you will learn.
V. … and you will learn. (…) No one knows how to teach you. It's … umm "I haven't read this book, so give it to me so I can read it". Well, but then you do your research and you see that no one has read it. They may have a … picture (emphasized). Each one knows things in their own area of expertise. But everyone is without direction.

Vasilis, father of a 6-year-old child diagnosed with autism

Vassilis, father of a girl with autism, who does not approve this diagnosis, describes how he discovered that the uncertainty he feels does not only concern him but all parents as well as professionals who deal with children with developmental disabilities. Unlike the parents in the previous extracts who emphasize on hope, the father here seems to be convinced that he is trapped in a form of total uncertainty, without direction. Using an example of actual directions, he highlights how there is not a single clue known about his daughter's condition, except that he must continue the research. Which leads him to a permanent state of uncertainty. For him, uncertainty and insecurity are part of the present problematic process: the only thing that is certain is that he doesn’t know. However, he himself appears quite dispassionate, probably because he considers himself aware of this unknown direction towards which he describes he is moving.

6.2.5. Satisfaction, pride and hope

Despite the prevalence of negative feelings, parents also reflect positive feelings on parenting a child with disability. Pride, satisfaction and hope about the child's progress are the most central positive feelings parents shared.

The mother in the next extract explains how she always believed in her son’s potential:

K. … I believed that he would make it.
ED. And more.
K. Yes. He has accomplished more than I thought he would.
(...)
ED. For yourself though, for Katerina, what has Katerina gained?
K. Katerina has gained pride. I feel so proud. I feel it.
ED. For what you did or for Costas, your child?
K. For all he has done.
ED. Mmm. For all he has accomplished.
K. For what I helped him do, but he is the one who has accomplished them, not me (…) He has succeeded on his own.

Katerina, mother of an 11-year-old child diagnosed with Alpha syndrome[27]

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[27] Alpha syndrome is a pseudonym of a rare syndrome.

Katerina expresses how proud she feels about her son’s progress. She always believed in his potential and he even exceeded her expectations. She notes, though, that it’s his own steps and her input was just to help him.

Feeling proud is among the focus of one of the group discussions as well; but for some parents that feeling was developed progressively:

E. (...) I catch myself … not now. When it was the 3rd, 4th time? Telling myself that I umm feel proud for, for, for having a child like this.
ED. Okay.
E. And I said it whenever I left from here. (short pause). And I believe that we should all be proud (her eyes water, weeps, voice breaks).
At. That’s what I feel before coming here. I mean it.
Mr. Hehe (chuckle).
At. I felt it before coming here. (…) I think that I couldn’t have anyone but Angelos.
(...)
E. I am proud of my babies. I mean, proud for having such a child in my life.
At. Yes.

Evangelia, Athina, Marina (group discussion)

Evangelia – mother of two boys, one of which is diagnosed with autism – argues on the sense of pride she feels, which she actually gained from her interaction within the group. This is about two different feelings she actually feels the need to differentiate: feeling proud of her children, meaning the common pride that every parent feels, and feeling proud of "having such a child". To her, parenting a child with autism means feeling proud despite the fact that her child has autism, probably to feel proud of her child as a whole, with his autism. Evangelia feels quite emotional while elaborating this, as it is a feeling she recently realized.

Another interesting point here is the group context. The mother discloses, with quite an emotional sharing, that the realization of her feelings is something she gained by joining the parents’ group, which she didn’t succeed in an out-group social context. It is as if the group context underpins or legitimizes the mother's pride in relation to her child with autism. The impact of the group context on parents is discussed in chapter 4.2.2.2.

Marios, in the following extract, reflects on this feeling of pride, analyzing the developmental steps of his son and how these steps generated feelings of satisfaction to him:

ED. When it comes to him walking, talking, and so on, did you feel happier when he did that in comparison to when your other children did it?
M. (whistles) Certainly! Certainly!
ED. Yes.
M. Look. You feel that … and … A baby getting its' first teeth, for example, or a baby walking is … normal if you think about it, umm it's expected.
ED. Mmm. Yes, yes, yes.
M. Right? Umm what does it mean for a child with Down syndrome to walk? It means that … we started physiotherapy on him ever since he was a newborn, until he was able to stand, umm … or until he was two years old, he was doing physiotherapy every week until his feet got stronger, and so on and so forth. It means that we have succeeded, our goal was exactly this, we worked on this, and we have achieved this. So there's more joy in trying to achieve something, and eventually achieving it. Instead of saying "okay, this will happen on its own", for example.

Marios, father of a 6-year-old child diagnosed with Down syndrome

According to the father, the progress is not about the evident developmental milestones that every parent expects, but an achievement that may have come as a result of a systematic effort on the part of the child and the parents. Every developmental step is a complicate process, including therapies, time and effort. Consequently, parents experience greater fulfilment when each developmental stage is succeeded, greater than that of a child with typical development. Unlike Katerina's previous quote, Marios here presents the child's developmental steps as a collective effort, using plural tense, achieved together by parents and child.

The bottom meaning of this narrative is the different representation that each developmental milestone has for a child with and a child without disabilities, which the father clearly states. The developmental step of walking for a child with typical development is a step of development, among others. The same step for the child with Down syndrome is a big achievement, which evokes great satisfaction for the parents.

The satisfaction because of the child’s progress is a common feeling a lot of parents share. It is quite obvious in the next group discussion:

I. When Nayia comes back from school, she shows us what she has learned.
(…)
ED. But you haven’t told us, how do you feel about it?
I. Yes, joy. Joy, joy.
An. Pride.
E. I think it gives you strength to … keep going.
I. Yes. And hope. (...) It gives you strength to not, to not … (unintelligible) your hands … And it gives you hope.
ED. To not give up.
E. To not give up, yes.
I. Yes. And it also gives you hope to keep going. (…) Or when you tell her “well done!”, “well done, Nayia!”, for example.
An. That ‘well done’. How loud can you say that?
At. A couple of days ago, for example, we went to the super market and for the first time, he always tells me “ah”, “aah”, “aah”. He touches things and says “aah”. And I don’t understand what he wants. He told me “I want a biscuit”. And I showed him three different biscuits (does a reenactment), “which one do you want?”
An. Hehe (chuckle).
At. He grabbed the one that he wanted. (…) I was really happy about it. That he expressed himself, that he told me what he wanted.

Irene, Anastasia, Evangelia, Athina (group discussion)

Athina describes how her son with autism verbally communicated with her, allowing her to be able after all to understand her child's desire and generating to her feelings of joy. Similarly, Irene feels contentment and pride from her daughter’s progress in school. Again here, as in the previous extract, the child's developmental steps are represented quite differently by parents of children with developmental disabilities compared to parents of children without disabilities. This representation potentially helps parents derive satisfaction from each child's developmental – small or taken-for-granted for others but huge for these children – step and create a condition of motivation and hope, which makes them feel fulfilled with their children's development.

In this particular group discussion, parents additionally emphasize in more detail what they gain from their children's progress. They develop strength to continue, hope and the feeling of not giving up. The idea of not giving up is a repetitive pattern throughout parents' words, when they describe their experience but also when they elaborate on their feelings.

6.2.6. Parents' feelings as a motivation for action

As it has been obvious so far, parents' stories included quite complicate and intense feelings. These narratives were often accompanied by references to their ways of acting and coping with these feelings, as it is described in Elena's words below:

E. (…) Umm okay, I can't say, umm I didn't break down. ***I didn't cry, um umm I was shocked but because I was really eager, and I still am, to help my child, umm you don't leave, umm it's were the knock-backs started happening.*** *Even at the kindergarten (…) Stephanos was going to. Umm where they expelled him. Umm it's when you start getting consecutive knock-backs, and you fall down, you get back up, you fall down, you get back up, but you keep moving forward. (…) It's like seeing a picture of someone getting hit, falling down, getting back up, and moving forward.*

Elena, mother of a 10-year-old child diagnosed with autism

The mother in this extract acknowledges the times she struggled, giving some brief examples of the incidents that led her to do so. In fact, she likens it to a real fight, putting herself in the place of the one beaten, who then gets up and carries on. The representation of the child's disability as a fight has been mentioned again by parents when describing their experience of parenting as a struggle (chapter 6.1.2.). However, the mother here emphasizes the zest she was feeling, which functioned as a motivation in order to take action for the benefit of her child and not let herself suffering.

Another similar manifestation involved the realization of mixed emotions at the same time or the inconsistency between the rationale and the emotion. The mother in the following extract exemplifies this pattern:

ED. Do you feel that … your rational thinking does not correspond to what you're feeling? Rationality and emotion?
M. They do. I realized from the first time I saw my baby that he has Down syndrome, even without having the confirmation. I was holding the baby, and on the one hand I was saying "yes, I understand, and I will try the best for my baby". But on the other, I was crying and saying "why?", for example.
I. Yes.
M. There is also that 'why'. But okay …
I. That 'why' …
M. … you're trying for the best.

Maria & Irene (group discussion)

Maria in this excerpt describes the very early stages of her child's diagnosis, where she was trying to acknowledge and understand the diagnosis. At the same time, however, she was experiencing strong emotions, crying and questioning 'why', which are indicative of someone who is mourning or has not yet accepted the diagnosis. Acceptance (discussed in chapter 5.1.3.) here seems to consist of two parallel but not compatible processes, namely intellectual and emotional acceptance. The mother's words reproduce precisely the experience of mixed emotions, along with the intention to act for the benefit of the child, even though she was feeling those mixed intense emotions.

Similarly, Antonia in the following extract suggests that she had intense feelings and emotional reactions, yet she remained active, coping effectively with the everyday demands:

A. Well, I have an ability that I can't explain. I am able to mourn, but still do other things.
ED. Ah, you remain functioning.
A. Yes. I do. My ability to function is not affected. I mean, he told us, okay, I went to the school, I saw it, I searched for different schools to see where I would take him, I informed the teachers, started taking him to occupational therapy, and went with him three-four times to see how Panos[28] works with him, I constantly asked Panos to tell me what to do, he told me, "if Philippos does this, do that". I told my mum, "if Philippos does this, you will do that". To his godmother, to my neighbor, to my dad. Umm, I started having this power.
ED. I think you left no stone unturned in informing people.

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[28] Referring to her child's occupational therapist.

A. Yes. Everyone. And I also had an infant (…) And when he told me that Philippos would be able to leave the house[29]*, I was holding the infant and Philippos, and we went where we were supposed to.*
ED. Yes. Really … (chuckle)
A. Yes. But I was crying at night. Or there were times when I was crying after leaving from the playground. But I kept taking him there.
ED. So there was something that kept telling you not to give up.
A. Yes. Yes. Now, even now. I have this. I may mourn for Philippos, or say "oh Philippos … mmm" but I keep moving forward. I keep doing my research …

Antonia, mother of a 6-year-old child diagnosed with autism

The mother describes the efforts she makes for her son, researching, investigating, gathering information, practicing and learning others to do so when they take care of the child. At the same time, she experiences feelings of sadness and mourning when she is not in motion or alert for her child. This effort was not affected by other situations, i.e. caring for the other child who was an infant at that time. There is a strong element of solution focused acting on the mother's part: whatever the circumstances, the mobilization of the parent for research and information must be done. Consequently, everything else becomes a second priority. Mother's feelings can wait till the evening to get articulated and infant care can be done on the go. This kind of emotional multitasking includes mixed and at times diverse feelings: pain and mourning, but also decisiveness, readiness and action-taking.

Parents' described a shared pattern of continuing to function quite effectively regardless of their feelings, which most of the times are negative and potentially restrictive. Parents seem to enter a state of alertness for their children with disabilities: everything else goes into second priority. Through this theme is again reflected the parents' tendency not to quit, which consists a recurring pattern. Parents' don't give up, no matter how adverse, mixed or diverse feelings they experience.

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[29] Referring to the child's need to go out of the house for necessary socializing, therapies, education, or else.

6.2.7. Summary

Parents reported several and intense feelings on their journey of parenting their children with developmental disability. Anger, questioning why and a sense of injustice are central in the parents’ narratives. Another group of feelings the parents report regarding their parenting experience is anxiety and fatigue, usually on a long-term basis. Some parents describe feelings like pain, loneliness and trauma, feelings often reported in cases of depression or bereavement. Other parents experience feelings of uncertainty, insecurity, fear, frustration and guilt while raising their children with developmental disabilities. However, parenting a child with developmental disabilities is also reflected in positive feelings for some parents, like pride, satisfaction and hope regarding the child’s progress. It is interesting, though, how the negative and the positive feelings co-exist in the parents’ experience of raising their children with developmental disabilities. Finally, some parents describe their feelings as a motivation for action, thus continuing to function efficiently despite their intense feelings.

Figure 6.I. The feelings of parenting children with disabilities.

6.3. The resources of parenting children with disabilities

Another central area of discussion in the parents' interviews was how they manage to handle an admittedly demanding everyday life. There were various activities or values from which parents seem to generate strength throughout their experience raising their children with developmental disabilities. Not all parents share the same, but the resources used by them in their everyday life are clustered into four themes: the *everyday practices and* *rituals*, the *religious faith*, the *trust in human power* and the *research and learning practices*.

6.3.1. Everyday practices and rituals

Some parents adopt various activities and practices in their daily life. The mother in the following extract explains how she feels benefited by going for walking or spending time to socialize:

ED. Umm Theodora, besides the … activities you do for (emphasized) Petros, are there things you do for yourself?
T. Umm, yes. Umm you mean …I do, yes. Umm … I may go for a walk. If I'm not tired. Or … umm I may go for a walk. Or at least once a week, or possibly two times week, I will go for a coffee with a friend of mine. That's what I do. In the morning.
ED. What does this offer you? What does going for a walk offer you?
T. Mental calmness. I like it, I enjoy being in nature. I've always liked it. Not because of Petros, I always did. I like being in touch with nature. It calms me down. It relaxes me. (…) Because I need it.
(…)
ED. Does going for a coffee or for a walk bring you relief?
T. Yes, because I do something for myself, umm for me, Theodora, I relax, I don't have to think about Petros, his needs, I can take care of Theodora, so I can be alright in order to take care of my child.

Theodora, mother of a 6-year-old child diagnosed with autism

Theodora chooses to go for walking and socialize, activities that she practices systematically and not every once in a while. Walking gives her "peace of mind" through the contact with the nature, relaxation and tranquility. The function of these activities is significant for the mother, since she reports that she needs both of these activities. Both walking and coffee with friends enable her to put herself as a priority for a while instead of the child, to take care of herself and get benefitted herself but also indirectly her child.

Other parents choose the physical exercise as a form of self-care. The mother in the following extract exemplifies this practice:

ED. I wanted to ask you if there's something (…) a habit, an activity, that can offer you relief from your emotions.
D. Mmm yes (hesitantly). I basically started going to the gym in September, but because of Covid … I avoid going to the gym.
ED. Do you feel that is has helped you?
D. Umm I don't really think so. Hehe (chuckle).
ED. Hehe (chuckle). But you said you'd do it anyway, hehe (chuckle).
D. But maybe, maybe your body gets tired and … you may stop thinking about things that you normally would, things you would overthink about. … You get tired and exercise your body there. It's something … But okay. I mean, because hormones and the physical aspect … certainly help. It's not that it solves … the issues. It's just a … it offers assistance. Let me put it this way.

Demetra, mother of a 6-year-old child diagnosed with Alpha syndrome[30]

Demetra focuses on the physical benefit of exercising. Additionally, by going to the gym she recognizes that the mental worry is limited or stops. This is an argument brought by other mothers, as well, like Theodora in the previous extract. Similarly, Elena describes how she enjoyed talking with other people or talking about other people's concerns in the gym, which made her not to think about her son's issues anymore and experience a kind of change (*… I met with other people, we talked about other things … It changed … my mindset (…) You felt yourself change as well).* For Elena, this social interaction in the gym marked her contact with the "outside" world, talking about issues other than her son's needs, which she believes gave her a "positive psychology" (*Doing, um, going into different situations is good for your mindset, you start seeing things more positively (…) What helps me, is interacting with the outside world*).

Another activity that some parents seem to use as a resource is taking care of their appearance. Andriana refers to how she started paying attention to her external appearance, for example doing her hair or buying clothes (*Umm lately I started paying some attention to Andriana … In general, I want to follow a schedule in order to pay some attention to myself*). Accordingly, Elena emphasizes especially on dressing up, for which she decided to wake up earlier, considering that it enhances her psychological state (*It's important, for your psychology, to get dressed (…) To powder your face a little, see that you look nice … It's good for my emotional health. And I started doing that, every morning … I woke up at 5:30 in the morning*). Apart from physical practice, socializing and taking care of

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[30] Alpha syndrome is a pseudonym of a rare syndrome.

their selves, other parents mentioned watching sports or cleaning the house as practices that helped them is some way.

Other parents describe some form of ritual they use, which relieves them of the feelings they are experiencing. Katerina gives a good example of this practice:

K. Even if I cry, it's hard for me to cry (…) I try to be alone whenever I cry. I don't want to be with my friends to caress me or … not. I try to be alone, to grab a pillow and scream into it to release this … burden I have. It mostly happens for two days. I also talk to myself in the mirror often hehe … (chuckle). I do things like these too. (…) I write often. I can write about any negatives, write them down, and then rip the paper, burn it, and that makes me feel better!
ED. Did you come up with these yourself or did someone tell you about them?
K. No, I read about them and I do them.
ED. Okay. The things you write, what are they? What do you write?
K. For example … they told me, "look, Costas will not make any progress, you definitely have to stop doing this because he won't make any progress either way".
ED. That it doesn't help.
K. Yes, that it doesn't help and that I must stop. Whereas I believe that it helps and I want him to continue doing it. I may go home and start writing, "it will help, there will be progress, I don't want to hear anything", "it will help" … hehe. (laughs).
ED. Yes.
K. I may write it down 10 times, then close it. A few days later, I will read it again, then close it. And whenever I feel like I made a decision that I will stick to, regardless of others saying that it won't help, I rip it, and I throw it away. Personally, these things help me. (…) Or we write down the things we want to achieve and we keep them in a box, and we rip those we don't want. These are the things I started doing. We talk to ourselves a lot, I said to myself very often that I'm strong, that I will make it … I looked at … (unintelligible) and said "you're strong", "you will make it", "definitely", "not today? Tomorrow".

Katerina, mother of an 11-year-old child diagnosed with Alpha syndrome[31]

The mother describes how writing has helped her to cope with the difficulties of parenting a child with disabilities. For her, writing is a means to reinforce her beliefs towards her goals and to sustain her faith in her actions. For instance, she writes down statements about her

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[31] Alpha syndrome is a pseudonym of a rare syndrome.

son which she considers negative and rejects them, or expectations she hopes will come true. It seems that by writing she reinforces the motivation to continue but also decompresses from difficult thoughts.

The mother's mental placement seems to be an essential central point of this ritual: if I want something I keep it and if I don't want it I throw it away. This symbolic movement – keeping or rejecting – represents for the mother a real movement (namely retaining in a box), related to important decisions for her child or to managing the emotions that arise from these decisions. Additionally, she seems to be practicing this ritual as a form of coaching on herself, enhancing her decision-making skills, using these strategies to support herself in her parenting experience.

Another form of ritual some parents seem to adopt is the religious ones. Elena, in the following narrative, describes how she feels benefited by the prayers – on site or at home – she makes:

ED. What does this prayer offer you? How do you think it helps you?
E. I feel like it offers me a moral, a satisfaction that I will be able to calm down. And most of the time, I do calm down. I calm down. (…) Umm yes, there are times when I happened to come, to read, umm simply a 'prayer to make you feel good'. 'Prayer umm to calm your soul'. (…)
ED. Have others given you these prayers in writing? Or let's say … are they prayers you create, you improvise?
E. No, something, umm I read them. I read them.
ED. Ah you find them on the internet?
E. Yes (…) Umm now we have, umm, I find them online, I download them and read them. Of course. (…) That, okay, umm there have been times that I searched for some remote chapels (…) I recently took Stephanos to Ayios Efrem. Umm we venerated, there were no priests there, umm that day. Umm I don't know, Eleni, sometimes I feel the need to go there and venerate. To have a prayer read to me, I went to Saint Kyprianos two times. Sometimes I feel it intensely and I do it. And I feel good. I feel, I feel better.
ED. Mmm, hmm.
E. You usually know when it happens, that's what I have noticed. I don't immediately feel better. I just feel like I may have calmed down. But as the days go by, I go, um I feel really positive! Umm I certainly feel better as the days go by umm … and I say "oh, it's because I went to church". (…) Umm I think I notice it as well. That it has affected me positively. Um

I feel it, I notice it on me. That I have … more strength … some things may come up that confirm to me that what I felt, or thought, or anything, it comes to me as confirmation … about something.
ED. Yes, I understand.
E. That's how I feel when something comes up umm … “ah, thankfully I did that, because look what happened”.

Elena, mother of a 10-year-old child diagnosed with autism

The prayer gives the mother “moral satisfaction” and helps her calm down. The mother does not seem sure what exactly it is that is helping her, but she feels stronger, she feels that she has contributed to a certain extent with her prayer to the flow of incidences. Besides, most of all she emphasizes the need to pray or kowtow. What the mother describes works somehow as a "self-fulfilling prophecy": precisely because she has the need to feel empowered, when she reads the prayer she feels that she is getting strength from that prayer. Thus, there is a mental process, a combination in her mind of this ritual – which calms her down – to the content of her prayer. However, it is herself that generates the power which she supposedly receives because of the prayer. A probable interpretation of this might be related to the fact that the prayer makes her feel calm: precisely because she calms down through the prayer, she also feels readier and not the same stressed to face the challenges of parenting a child with disabilities, which makes her feel stronger.

6.3.2. Religious faith

Except from the prayer as a ritual, the religious faith emerged as a central theme in some parents' stories. The main trends were related to *the faith as a support* for the parents, to th*e strengthening of their faith due to their children’s disabilities* but also to *the loss or testing of some parents' faith*.

Religious faith represents a significant support for some parents. The father in the following narrative exemplifies this representation:

M. That’s an interesting question. Look, umm … in general, umm … it supported me. Okay? The fact that I have faith supported me in many aspects of my life. Just like Christina has, because we have similar opinions. But my faith has helped me. In the sense

of hope. According to Christianity … there are three main virtues: love, hope and faith. Umm for me there is also expectation, the hope that things may go even better. Umm and there is also the faith in care. You accept that. Even though you may see things that make you think that there has been no care. Okay? For this issue to exist. Nevertheless, according to Christianity, you should believe that there is care. You may not know it, but you believe that care exists. You believe that there is care, there is nurture from God.
ED. Ah. Ah aah.
M. Right? In that sense (…) The other one is giving. If you give yourself to something, to change it, in a positive manner, to change, to help, to do something. Umm okay, I'm talking about my child in my case. Not in a broader sense. Right? That's something as well. It gives you courage to keep going. Okay? Faith has helped me. You trust what you feel. Well, that's how I experience faith (…) What I feel is that there is care, umm from God about it. Okay, all this is a personal testament, it's not a guarantee … of truth. Or … the part which involves a more active engagement with faith (…) Yes, specifically, a priest helped us. Okay, but it's … okay, this is a person who has remarkable umm … pfft spirituality and culture, this priest. His saint … (unintelligible) who got us married. Okay? Umm … there's also our religious mentor in Athens, of course. Okay, he's a writer, who has … artistic and literary interests … he's a writer, he has written 4 books. (…) And he helped me, by umm guiding me to give. Namely, that it's better to look after Antonis, and provide him with love, umm and help with his issue by doing that. Instead of sitting and thinking umm … umm why is this happening to me, and so on. It is a discussion that leads to nowhere. And this (emphasized) helped me so much. Okay?
ED. Yes, yes, yes.
M. Okay? And I think that was his most important contribution in his matter. Okay? I didn't go to this priest to tell me whether my child has an issue or not, he is not a doctor. Okay? Okay. He's not a therapist either, nothing … of the sort. Okay? I went to him for myself.

Marcos, father of a 7-year-old child diagnosed with autism

The father analyses how the three virtues of the Christian faith – hope, faith and love – helped him reflect regarding his son's autism. According to him, the faith in God's care is not anyhow proven but is presented as helpful and works in relation to hope, through the expectation that things will turn out well. Love is about his trust that faith will help him. Via this triptych, he seems to have the proper resources in order to feel supported and to feel the strength to continue.

In terms of practical help, this came from the priest from whom they received support as a couple, since he proudly shares his religion belief with his wife. It is interesting how Marcos highlights that he addressed to the priest solely for him and not for the child. Marcos also feels the need to emphasize the educational background of the priest. Being highly educated himself, he chooses to explain this underpinning philosophy of his religious faith. Education here seems to add legitimacy and significance to his argument of faith, as opposed to the rhetoric of blessing, prayer and regret, as claimed by Elena (previous chapter) and Marina (following extract), which is based only on their personal testimony.

Unlike Marcos, Marina underlines how the blessings partially contributed to her daughter's wellbeing. Particularly, she gives her prayers a more utilitarian and less symbolic meaning *(I took her to walk in Jerusalem, on Jesus' tomb. We received huge blessings. I believe that I owe a part to … we went there, we pleaded, we cried, we venerated. We repented*). The mother focuses on the practical and useful for her part of praying, the prayer as a request from God and the benefit of the prayer. It is interesting how she highlights the place of the prayer, as she took her child in the so-called center of Christian faith. According to her, the onsite prayer and the pilgrimage help the faithful people achieve repentance and blessing. In that sense, her daughter with disabilities was greatly blessed and benefited by the onsite prayers of the family.

Other parents discuss how their religious faith is strengthened after their children's diagnosis. The mother in the following excerpt gives a good example of this approach:

I. God was beside us, he helped us, he gave us strength. I believe so much in God. Both Anastasios and myself are miracles for even being here and breathing.
ED. Mhm. What you say is nice.
I. My blood pressure reached 190 while I was in the surgery room, I am really lucky to be sitting here talking to you. (…) Having this faith in God … helps me. (…) Prayers, when I pray … I know that God hears me, I know that he's beside me. He gives me strength every day.
(…)
ED. I want to ask you, where do you draw strength from? Where do you draw energy from to … keep going?
I. Umm … from God (laughter), everything comes from God. I am … really close to God, more than I was the day I gave birth. When I saw that …
ED. You didn't believe as much before that.
I. I did, I believed. I prayed, not as much as I do now, after seeing how big of a miracle we are … Well, this belief in God changed me.

ED. Okay.
I. Okay, I believed, but I didn't believe in miracles as much. After I saw the miracle of Anastasios and myself … From God.

Ioanna, mother of a 7-year-old child diagnosed with cerebral palsy

Ioanna is a deeply religious person. When her son was born, 7 years ago, she felt God next to her, truly believing in his help. The mother clearly speaks of strengthening her faith since the birth of her son. The reason behind this change is the representation of herself and her son as survivals by miracle: they survived thanks to a God's miracle. While she used to believe in God, now she also believes in God's miracles. Additionally, it is interesting how Ioanna seems to declare blind trust in God, which makes her feel stronger in order to cope with her son's issues now and in the future.

In a similar way, Elena discusses how she came closer to God in recent years, with the experience of parenting her son with autism. However, she gives a detailed explanation of the reasoning behind this empowerment of her faith:

E. When it comes to me, as Elena, I really believe in God. Umm I believe, after Stephanos was born I can say that umm, I feel closer to God, because I really umm believe that the strength we receive comes from God. Umm because our daily life is difficult, umm no umm … And a lot of times it becomes umm really intense Umm … But we umm have a supernatural strength (emphasized) to persevere, comparatively to how I used to be, and how much I could withstand before. After having Stephanos, I see that I have gained, I have developed great endurance. Endurance that I didn't know even existed. So I believe that … umm I draw my strength this way from God. Umm he provides, God watches it and provides me with strength. These are my beliefs, they may be irrational, but that's how I feel.
(…)
E. Well, look. Umm the, umm one of the stages that us parents go through, okay, most of us, is believing more in God now, we turn to the church more, we draw strength from there.

Elena, mother of a 10-year-old child diagnosed with autism

Elena's faith was also strengthened by her son's disability. The mother reflects on the challenges she experiences everyday due to her child's disability, which she believes she can manage because of the power provided by God. She also describes a "supernatural" power that she developed, with many more strengths than in the past, which she does not attribute to herself but directly to God. Therefore, since she gets power from God to continue, she also stays close to God, closer than before. Consequently, God is aware of her strength and keeps supporting her. This is something that, according to her, is common in all parents of children with disabilities: they come closer and believe more in God, precisely because they get strength from God. It is even remarkable that in most of this extract, she uses plural tense, as if she is discussing this theme on behalf of most parents of children with disabilities. Interestingly, however, the mother acknowledges that her argument lacks evidence, something that Markos also pointed out in the previous narrative (*it's not a guarantee … of truth)*. Here Elena prefers to emphasize that this is how she feels the empowerment of her faith, even though it may sound somewhat absurd to someone.

On the contrary, some parents report losing, questioning or testing their faith because of their children's diagnosis. The mother in the following extract exemplifies this loss of faith:

E. Let me tell you something regarding religion. I used to be very religious. I went to church every Sunday. I distanced myself from God.
ED. When Aris' issue came about.
E. Yes. I distanced myself. Not because he sent (emphasized) me Aris with this issue. With this particularity. But because he makes me go through this process of fighting (emphasized) every day, umm … for the most obvious things. For my baby to receive what she is supposed to have in this society. That is why I distanced myself. And I don't know if I will ever find the strength to ever come, closer to … I used to always make the sign of the cross, or I would say "mother of God", "oh my God", and so on. But I distanced myself.

ED. You used to go to church but you don't anymore.
E. I don't, no. Umm but what I, I believe in my own strengths. I believe in my own strengths. (…) Because that's what I always used to discuss with my religious mentor, for example. (…) "There is no explanation", he used to say. "Everything, for … everything for … everything happens for a reason", he said. And I told him "I don't understand this". (…) There are things that I don't understand. Someone should explain them to me.

Evangelia, mother of a 6-year-old child diagnosed with autism

Evangelia describes losing her faith in God since her son's diagnosis because religion failed to provide an answer to her on why she has to go through this process in her life. Having no answers, she chooses to question God's will, to distance herself from religion and start relying on her own strength.

The mother seems to question the power of God. This question is not new in the parents' narratives. Particularly, Georgia (chapter 6.2.1.) had similar questions, followed by anger feelings, concluding that God does not make everything perfect, also declaring that she lost her faith in God. In the similar way, Demetra felt betrayed and angry towards God, after the birth of her daughter with a rare syndrome (chapter 6.2.1). Her own distancing from the faith was expressed by refusing to adopt the customs of the faith (taking the candle of baptism to the church), which she delayed for about 5 years, emphasizing that during this time of questioning God she felt stronger herself and readier to reconciliate with God, but not to accept his power.

These stories regarding the parents' faith seem to create some form of pattern. Many parents declare that they believe in God, acknowledging there is no perceptible testimony or evidence about this faith. However, when they face big questions concerning their children, which cause them strong feelings and possibly traumatize them, they doubt God's perfectness and they feel losing their faith in God. Instead, they begin to believe more in their own strengths, which they feel they can manage, understand and trust more.

6.3.3. Trust in human power

Another significant resource for parents of children with developmental disabilities is trust in human power. This trust has to do with *the belief in their child's potential*, the parents' *belief in their own power* but also *in other people's power*, i.e. professionals or other parents. The main source underpinning this trust in human power is the hope for the future. Some narratives are quite representative of this theme. Demetra gives a good example of this trust in human power, while talking about her relationship with her daughter's doctor:

ED. The, the matter of faith, what part does it play in this … umm in this co-operation, but for you personally as well.
D. Umm it is the most important part.
ED. That, that he believes in the child and in you, possibly.
D. He believes in the child. As for me … what he tries to do is, is to do the things that need to be done. (…) It's the most … after the … umm it's the most important. (…) What

everyone around me says all the time is “ugh, Natasha has to try”, “she must…”. As if … this … issue is presented negatively. (…) the rest of the therapists (…) of course they umm … hmm they recognize that she is making a huge effort, but they don’t believe (emphasized) that she really has any capabilities to go beyond a certain point (…) They don’t really believe it (…) the most probable explanation is that they don’t believe it, because they have never managed to help a child reach their full potential. (…) That is, they can, they can, we can achieve things. As long as we believe that they can be done. And … I don't … I think that most of them don’t believe. That the children can … umm … they limit their, their capabilities. That’s what I don’t … I mean … what our occupational therapist told us, is what they say in the United States, for example, what they say at his University, that “the sky is the limit”.

Demetra, mother of a 6-year-old child diagnosed with Alpha syndrome[32]

The mother discusses the importance of faith, as a child can reach further and further in what can be achieved if there is a professional who believes in his/her capacities. According to her, most therapists do not really believe in any child's potential. On the contrary, the mother – through the child's doctor who inspired her this faith – declares that she has unlimited faith in her child's potential. The power of believing in what can be achieved can lead to actual changes. The mother continues on to describe how she has been inspired by another parent, an activist in the field of children with developmental disabilities:

D. Umm something really important that opened my eyes was (…) in my effort to find answers, I randomly found Julie Ioannou[33]*. It was the first time I went to a seminar organized by ‘love n hope’*[34]*. And I realized how much strength you can draw, and what a sense of direction you can get from other parents. It was the first time I … I felt that. And it was an amazing feeling. (…) Umm that woman specifically is so positive. Umm I mean … she must, let’s say, she must have … a healthy relationship with the rest of her family, with her husband, she views life positively. She doesn’t go through what I went through, I mean that umm I felt helpless, to … I didn’t have something to rely on, I didn't have any hope, I didn’t have whatever. So, in essence, she provided me with, it was the first hope that was*

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[32] Alpha syndrome is a pseudonym of a rare syndrome.

[33] Mother of a child with disability, well-known in the circle of disability issues in Cyprus for being a dynamic activist. She is activated in a Cypriot association of parents and friends of children with developmental disabilities.

[34] Association of parents and friends of children with developmental disabilities (renamed by using a pseudonym).

provided to me in the whole situation up to that point. Julie was the first hope I was given. She opened my eyes to … what it was about and what happens (…) The first hope I was given was Julie. And the second one was our … current occupational therapist.
ED. Mhm. Are there any … values that have influenced the way you look at this matter?
D. Yes, basically … umm … I learned from my family to insist, to not accept things. I mean, I learned how to insist on what I want. Umm I think that's why … I maybe can't accept some things. For example, I can't accept that my child will never be able to do a certain thing.
Demetra, mother of a 6-year-old child diagnosed with Alpha syndrome[35]

The mother received much strength from another mother of a child with disabilities. She does not fail to mention that this particular woman's strength and positivity was influenced by her healthy relationships within her family, something she lacks herself (divorced, single mother, with limited support network). The mother seems to want to communicate the message that hope is not auto-generated, but is built through strong foundations and healthy relationships.

The concept of faith, as presented here, is inextricably related to hope: only by believing in certain things, one can make them happen. She cannot compromise with the idea that her child will simply progress or will not even progress in a developmental area. She firmly believes in and fights for her child to reach her full potential, which gives her strength, hope and perspective for the future, something that therapists fail to do. The trust in human power seems to become a circular process for the mother, utilizing the existing human resources and representing her child's issues as possibilities and not as problems to be solved, she does not accept anything less or quit the struggle. The continuous struggle brings, among others, some good results, which makes her feel confident and gives her a solid basis to keep going on her every day fight.

With the same reasoning, Ioanna in the next narrative emphasizes on her belief on the potential of her son rather than on the problems and what he cannot do:

I. He was born and the problems arrived with him. That's how I view it.
ED. Okay. So, it's like …
I. I can't just say, "Anastasios was unable to do that", because I would have gone crazy if that was my way of thinking for all these years. I couldn't afford to think like this all the time. I kept telling myself that "I am lucky to be here, and Anastasios is lucky to be here,

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[35] Alpha syndrome is a pseudonym of a rare syndrome.

lucky to be well, to be healthy, we will be strong, we will always be there for him (…).” Well, because if I resigned myself to … to thinking that Anastasios is unable to walk, that he is unable to do this, that he can’t… we would have gone crazy.

ED. So you believe that he will succeed and that he will make progress.

I. Yes, I do believe it. I have a lot of faith in Anastasios. He has the potential.

ED. Mhm. His … capabilities.

I. But there are parents that don’t … that don’t want to say that their child has special needs, that they are special needs children. (…) I know that Anastasios has special needs. (…)

(…)

ED. How does it help you when you say that “I know that he has some special needs, but we are trying for the best”. How does that help? In which ways does it help?

I. Well … it helps that he is healthy, that he is happy… progressing. That he always …

ED. Okay. That he does things, that he makes progress.

I. Yes. That he makes progress in his life, and I have faith that he will make more progress in his life. And that someday he will be able to talk (smiles).

Ioanna, mother of a 7-year-old child diagnosed with cerebral palsy

The mother describes her son’s problems as issues that “came with him”. However, the mother consciously chooses not to focus on what her child cannot do but on the constructive parts of their experience, such as that she and the child survived a high-risk delivery. Ruminating about the things that her son cannot do is, according to her, a one-way road to madness. The mother here introduces another interesting dichotomy: hope versus despair. People cannot live without hope, since in case of despair, it is not possible to proceed. Therefore, for Ioanna, believing in her child's potential is a one-way route, because only in this way she can build the hope she needs. What helps her is the strong trust in her child's potential, recognizing the child's diagnosis but having a deep faith that he will progress and go even further in the future (*someday he will be able to talk*).

Apart from the belief in the child’s potential, the faith in their own power is also central in parents’ stories. The following narrative exemplifies this consideration:

ED. I would like you to explain where you draw your strength from.

A. Ah (takes a deep breath). From within me. I am strong.

ED. Is it, do you think …

T. I have enough strength.

ED. … your character is like this.

T. Yes, yes. Yes. And because umm … I keep thinking, I find ways out. Namely, I understood from the first moment umm I always found α way out in my life, no matter the problem I had to face. I was able to find ways out. And I understood from the first moment that I had to approach other parents, that, I felt that I, as Theodora, wanted to find support from other mothers who are going through the same thing. Although I had close familial bonds, I, as Theodora, felt like I wanted to talk to someone who is going through the same thing. It would bring me relief.
ED. I see.
T. To me, as a person. I pursued it and I did it.

Theodora, mother of a 6-year-old child diagnosed with autism

Theodora describes assertively an inner strength that has helped her find solutions in any situation in her life. Regarding her son's autism, she realized from the first moment her need to find other parents experiencing similar issues, to talk and get support. It is interesting that the power the mother discusses makes her more goal and solution focused and, therefore, more effective about what she is dealing with.

Even though sometimes the parents cannot easily identify what is helping them, they recognize their inner power as a strong resource for them. For instance, Athina, during a group discussion, is presented thoughtful about the resource she uses, yet ending up in the faith in herself (*At. …* I don't know what it is that gives me [strength] (…) To ourselves I think, I don't know [we believe]. *That is, you want to also prove to yourself that … I don't want to be like this*). The belief in oneself is a means in order to prove her potential, to prove that she hasn't failed – meaning an undesirable status – and that she keeps going. Without the point of doubt, Anastasia, during the same group discussion, reflects a sense of confidence that she always felt that she will be fine (*An. I always felt that I was going to be fine, whatever was …* I knew that someone has … has intervened and that I could face whatever would come my way). The shared point of this group discussion is the belief in their own power.

6.3.4. Research, information and involvement

Another resource that seems to be important for parents is knowledge. Most parents, just after their children's diagnosis, seek to research, to learn and get involved so as to gather information about their children's condition. Some parents discuss about specific information that they found helpful, such as the mother below:

C. Have you heard of "The Reason I Jump[36]"? It's the book…
ED. Yes, yes, you were the one who told me about it.
C. It's, it's amazing, because one person with severe autism explains what he feels when he watches the news, when he jumps, when he watches the whirlpool go away (makes a circular movement with her hand). And in the end, he rationalizes what seems out of place and very senseless, disconnected from the reality of others. I enjoyed (unintelligible) reading it very much.
ED. Well, the author is someone with autism and he is now an adult.
C. Yes, yes. He is from Japan, I can't recall his name. Doctors wrote him off when he was a child that "he wouldn't…". His mother was the one who supported him, and tried to communicate with him by using computers – because he was also unable to speak – to … to reach that hidden world. (…) I read so much.
ED. Do you think reading helped you? Because, okay, the internet is a 'rumor hub', where you can find infinite things …
C. Okay. Since I know how to search … I knew what to search. (…) I knew how to do it, I wanted to see, I watched … I watched videos, I instantly joined communities. That's my nature. Right? (…) So I felt … because my child exhibited the things I read, I felt safe that what I read was correct.
(…)
ED. Umm … this book, "The Reason I Jump" … how did it make you feel?
C. Oh my goodness. I cried so much, Eleni. I cried so much. Because it is disheartening to see how we feel, and how people on the outside understand. He jumps, for example, and you yell "why are you jumping?", because he will get hurt, because he doesn't sit in place, because he will ruin the couch, because, because, because. And you see how much he needs it to be able to define himself within the space. (…) And you say "okay, okay, how stupid am I?" I'm telling you, it's this, you're opening up to something different. This … emotional and mental spaciousness, is …
ED. So it's to better understand …
C. You get inside your child's head and you are able to see how much he suffers (…) So, they don't … what can I tell you, Eleni. It was shocking to me. It shocked me.

Christina, mother of a 7-year-old child diagnosed with autism

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[36] Higashida, N. (2016). The reason I jump. New York. Random House. https://www.penguinrandomhouse.com/books/227014/the-reason-i-jump-by-naoki-higashida/

Christina begins by describing how a book written by a person with autism has shocked her and inspired her to understand the perspective of people with autism. Behaviours that seemed incomprehensible to her and to others made sense and allowed her to understand her child. For her, reading seems to give her strength and security through the possibility to understand her child, to open new horizons and perspectives of understanding. The interesting in the mother's argument is that she contrasts what a person with autism looks like and what they really are, which this book revealed to her. At the same time, this book also emphasized to her the potential of people with autism, even low functioning, since by explaining their behaviours they are able to communicate with others and also communicate their ideas, like the author of this book.

Research and involvement helped some parents find relief by acknowledging what they have to deal with. The father in the next extract describes this consideration:

M. Umm … okay, I remember (…) I didn't talk to anyone, but I searched on the internet to find what Down syndrome is. I looked at other children with Down syndrome, umm … I immediately found – because there was not one in Cyprus – I talked to the Down syndrome association of Greece. Umm … I looked at kids and so on. (…) I'm telling you, I was reading, I wanted to get to learn about Down syndrome. Umm …
ED. The things you did, searching on the internet, and so on, calling the Down syndrome association of Greece, did they offer you relief? Were they helpful?
M. Umm it was helpful since …when I saw other kids with Down syndrome in videos, photos or … kids who were able to run, who were able to speak, who were able to play football, who were able to cycle, who were able to …
ED. Therefore …
M. It helps because … my child does a lot of things … it's not, it's not the end, it's not the end of the world, let's say, for …
ED. Yes.
M. I remember reading about Pablo Pineda[37]*. Who finished University.*
ED. Who became a teacher.
M. Who became a teacher. I read about another woman in Cuba who became a dance teacher (…) So you feel some relief, okay. You see that things are not as tragic as you thought they were. (…) Umm after Christos' birth, because I searched to find on my own what Down syndrome is, I ended up searching through the Down syndrome association of

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[37] Spanish activist for the rights of people with disabilities and the 1st university graduate with Down syndrome in Europe. He has worked as a teacher, actor, he has written books and now is working as an awareness consultant.

Greece. Umm … before Christos turned one year old, we went to Greece, we visited the association in Greece. We met others who have children with Down syndrome – that was really helpful. Umm we came back, and we also met children with Down syndrome here in Cyprus. (…) You see umm … things are clearer, clearer in your mind, you know what you have to face.

Marios, father of a 6-year-old child diagnosed with Down syndrome

Marios testifies how the direct contact with families with children with Down syndrome helped him to normalize the experience of the syndrome and to realize himself that children with Down syndrome live a 'normal' life. The father observes that the living examples were the greatest source of relief for him, because this helped him to challenge the tragic representation he had built about them in his mind. The focus on the 'normal' elements of a child's life, e.g. playing or talking, seems to inspire him feelings of safety and relief for not going in a completely unknown direction. Besides, this feeling of safety through the 'normalization' of the syndrome experience provided the father with enough resources and hope to continue towards the future (it's not the end of the world).

Knowledge as a means of reducing uncertainty and anxiety is a pattern reported by several parents. For example, Yiannis refers to an inversely proportional correlation between information and uncertainty (*… the better informed you are, the more you umm … lessen the, let's say, the umm … the range of uncertainty*). Another common argument that several parents share is the initial thirst for knowledge. Many parents felt the need to learn, to get informed as much as they can in order to feel readier to help and offer support to their children. Elena exemplifies this practice, still continuing her research after several years and learning new information that she applies in her life (*… you get something from every expert. I have to admit that even now, as we speak (…) I have applied umm things in my daily life (…) to help my child and myself*).

In addition to practical knowledge, overall information about all aspects of the lives of children with disabilities and of their families was very vital and useful for parents. The mother in the following narrative emphasizes this perspective:

A. I told you, in the beginning, I didn't hear anything positive, and the truth is that I didn't feel well because I was anxious all the time. (…) And I searched on Google (…) And I found

the website Noah's dad[38]*. Umm which I still follow. (…) They didn't know that their baby would have Down syndrome either. He was also their first baby too, his mother is a doctor in the United States. And it felt like the darkness had been lifted, and I suddenly was in a sunny meadow.*
ED. Come on!
A. Yes. Umm … this person has started what's called a 'hope story', umm … that attempts to inform the parents, about what I told you, that yes, the child has Down syndrome, there are difficulties, different issues, but there are also positives. There's no need for 9 out of 10 babies to end up in the garbage can. They also have value. Well, I found this website and ..

ED. What … what is so different about this website?
A. Umm the approach. The website tells you clearly, there was a video where the baby, the baby was so happy … the website recommended toys, I bought that one first and then I always followed to see, the website suggested nice toys that were suitable for the children. Umm the website always showed how happy the child was, umm regardless of difficulties, and so on. It was really important to me as well. I mean …
ED. How did this website affect you?
A. Very much.
ED. How did it make you feel?
A. I was over the moon. It made me feel happy. I still feel as though that baby is … mine, is part of my family, let's say. Because … yes, I think he is two years older than Petros, he must be 10. (…) That child is always happy, umm … his parents are happy, they have no reason to be sad. And that's how I changed, my mood changed. I saw … "oh! This is the face of Down syndrome".
ED. Okay.
A. This is the face of Down syndrome. And not all these things you hear, all these "but…", and "maybe". This is what you have in front of you. You have a baby who is happy, who plays, who laughs, who is healthy. That is the face of Down syndrome, and not the others. That website helped me very much. Very, very much.
Andriana, mother of an 8-year-old child diagnosed with Down syndrome

Andriana, in her attempt to get informed, discovered the blog of a father of a child with Down syndrome. This particular page made the mother feel relieved, because she felt that children with Down syndrome don't only have problems but are also worthy as persons. As previously discussed by Marios, the contact – even the virtual contact – with another family with a child with Down syndrome and the positive approach of the blogging father, helped

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[38] https://noahsdad.com/

her to demystify and also normalize her child's syndrome. This approach allowed the mother to realize that children with Down syndrome have a life worth living and do not deserve to be rejected by society. Additionally, this consideration made the mother release her stress and feel that she is raising a child like any other mother, thus made her feel normal. This ‘normalization’ contrasted with the anxiety due to the problematic representation of the syndrome that the mother initially had, where Down syndrome was identified as a negative and undesirable condition. On the contrary, this particular blog highlighted the positive and the hopeful perspective, that of children with Down syndrome playing and laughing and being happy. For the mother, this perspective seems as a disconnection of the representation of Down syndrome from misery and sadness. “There is no reason for them to be sad" (meaning the parents), as she claims. This argument is giving emphasis on the potential and not on what the child with Down syndrome cannot do, approach which is based on the Social Model of Disability (discussed in chapter 4.1.1.).

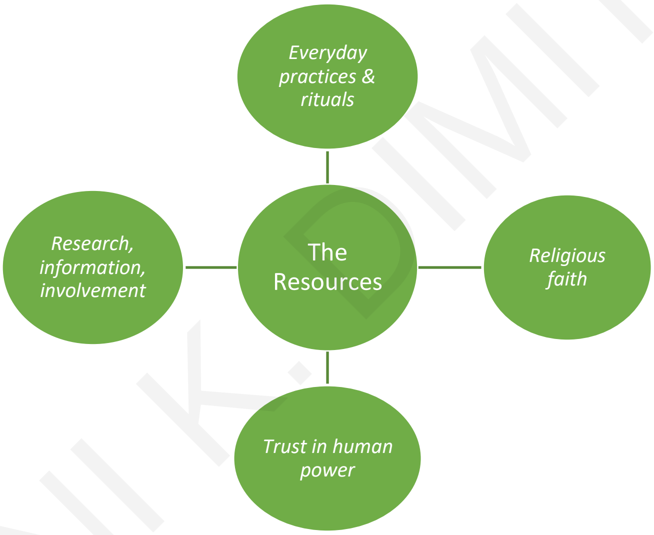

Figure 6.II. The resources of parenting children with disabilities.

6.3.5. Summary

The resources of parenting a child with developmental disability are vital because they provide parents with the required strength in order to cope. Some parents mentioned everyday practices, self-care or rituals – religious or other – as factors that help them handle the demands of parenting a child with disability. The religious faith is a central resource for some parents, representing a significant support for parents. However, some parents described losing or testing their faith because of their children's diagnosis. Trust in human power was also reflected in parents' narratives, namely believing in their child's potential, in their own power as parents but also in other people's specialty, like professionals. Other parents emphasize on knowledge – reading books, researching, involvement or following personal blogs – as an essential resource for them.

6.4. Bringing it all together

This chapter examines the experience of parents raising a child with developmental disabilities. Parents' stories demonstrated how they represent their experience of parenting a child with disability as a hefty burden, as a constant struggle but also as a blessing. Some parents make sense of this experience as a variation of the parenting experience: their children are different but their parenting role is not that different to any parenting role. Parents also reflect on the meaning of their parenting experience, by focusing on their lost expectations, thus what they feel they have lost because of their children's developmental disabilities.

Additionally, several feelings emerged during their narratives regarding their parenting experience, such as anger, anxiety and fatigue, loneliness and trauma. Parents also revealed feeling uncertainty and fear for the future. Positive feelings were also reflected, such as satisfaction, pride and hope. The association between these feelings and parents' actions is also discussed, since parents seem not to give up, no matter how intense feelings they experience.

Beyond the meaning and the feelings on their parenting experience, it is interesting how parents cope with this experience. Specifically, my focus was on the resources used by parents in order to manage their parenting challenges. Everyday practices and several rituals were frequently used by parents. Some parents derive strength from religious faith while others emphasize on the human power, believing in themselves or the child's potential. Knowledge and information were also an important resource for parents, through their research and involvement in relevant activities.

In the following section, I attempt to explore how these themes are related and connected to each other. Particularly, I argue about the spiral nature of the parents' experience, where seemingly opposite feelings and meanings succeed one another, throughout the parents' course of raising their children with developmental disabilities (6.4.1). Additionally, I claim that the parents use the contact with other parents as a 'normalization' coping mechanism, which enables them to normalize their experience of parenting a child with developmental disabilities (6.4.2). Finally, I discuss about the way parents generate hope despite the uncertainty they experience, employing cultural elements with symbolic meaning, namely symbolic resources, to support their efforts of meaning-making (6.4.3).

6.4.1. The spiral nature of the parents' experience

This study suggests that parents experience their children's disability as a spiral process, which involves their meaning and feelings of parenting their children with disabilities.

The findings about the meaning and feelings of parents' experience, as analyzed in this chapter, are consistent with previous studies. Caring for a child with disability is broadly represented in literature as a burden due to the added intensity and the extended commitment (McLaughlin et al, 2008). Griffith & Hastings (2013) discuss about the chronic strain of the caring role when parenting or caring for children with intellectual disabilities, describing it as a "fine balancing act of juggling care needs, challenging behaviour episodes, issues with support services and setting up services for the future" (p. 411). Families with children with intellectual disability report more caregiver burden along with problematic family functioning, less marital satisfaction and lower sense of coherence (Al-Krenawi et al, 2011). Additionally, literature confirms the parents' struggle, mainly on issues related to the public sphere, namely entering the school or getting support (Akerstrom & Nilsson, 2010). Parents' lost expectations have also been discussed by Landsman (1998, p. 76) as the "trauma of dashed expectations". Feelings of anger, frustration (Kearney & Griffin, 2001), sadness, fear and anxiety (Arbouniotis, Koutsokleni & Marnelakis, 2007; Solnit & Stark, 1961, Beresford, 1994; Lopez et al, 2008; Crnic et al, 1983) are in the core of parents' experience of raising a child with disability. Specifically, parents report significantly elevated levels of stress, which place them in a vulnerable position (Davis & Carter, 2008). Positive aspects of raising a child with disability and feelings of accomplishment are also supported by literature (McLaughlin et al, 2008).

Other studies attempt to add valuable insights not only into a single aspect of the parents' experience, as the above-mentioned, but to broaden the perspective of the parenting experience of raising children with disabilities. Kearney & Griffin (2001) describe dipoles of opposite emotions, with parents reporting feelings of joy and sorrow but also feelings of anguish and hope regarding the parenting of their children with developmental disabilities. Park & Chung (2015) propose the caregiving stress process model, where they present a multifaceted model of change and adaptation for mothers of children with disabilities.

Farkas et al (2019), in their study for parents of children with Down syndrome, suggest that the stress models focus on the deficits whereas there are also positives of parenting children with disabilities, which need to be highlighted as well.

Nevertheless, the existing literature predominantly explores the issue of parenting children with developmental disabilities using a one-dimensional approach. Parents either feel sadness, anger, stress, experience struggle or feel hopeful, namely focusing on a single aspect of the parenting experience. Most studies fail to examine how parents' feelings are related with each other and how the parents' feelings and meaning are related between them. How come some parents focus on the one side – burden, loss and sacrifice – and other parents on the other side of the experience – blessing, benefit and gain? Additionally, literature does not examine how some parents experience at times both negative and positive feelings and how they move between the two. Therefore, there is not a broad conceptual framework in order to connect each of these aspects of the parents' experience and to explore the process between them.

What this study suggests is that the parents' experience involves several aspects, which are connected with a circular way, creating a conceptual continuum, which I describe as a spiral (see Figure 6.III). Most themes discussed in this chapter reflect the upper or the lower aspects of the spiral. On the one hand, the child's disability is experienced as a burden and as a difficult and painful struggle, where the parents have to sacrifice, give all their strength and undertake an unwanted commitment. The child's disability is mainly experienced as a symbolic ending for the parent herself and her world; As stated above (chapter 6.1.1), Demetris, represents this experience as the end of his life. On the other hand, the child's disability is experienced as a blessing, which is clearly not the end of the world; an experience which might also be seen as beneficial by the parent. Elena vividly describes that as the end of a performance but definitely not the end of the world*,* where there are still plenty of chances to continue the effort and go on with one's life.

In other narratives, parents focus on the child's absolute dependence on the parent and on the need of sacrificing their own lives as parents; at the same time, though, the parents discuss how they benefit from the experience of raising their child with developmental disability, a life experience which makes them less selfish as persons. These apparently opposing narratives may also arise from the same parent. For example, Elena emphasizes that raising her child with autism is an emotional-draining ordeal, but at the same time she underlines how she has become stronger as a person through this experience, with nothing affecting her anymore.

Therefore, the aspects of the experience concern the end of the world – meaning a life-determining event, a critical turning point for the parent – versus the continuance of life in different terms. The aspects of the experience are also about the gain versus the loss for the parent. Some parents focus on the benefits they gained through their experience, like distinguishing what is important in life, discovering the meaning of life, interacting with upstanding individuals, self-development but also strengthening their personal faith. Other parents emphasize on their losses, like the expectations of a "normal" child and of an ideal family. Some parents focus on everyday losses as well, like relaxation, respite or feeling fulfilled.

Interestingly enough, some parents move from one aspect to the other. Namely, although they emphasize the burden of dependency, they nevertheless present their experience of raising a child with disability as a blessing or as a variation of the parenting experience, which is clearly not the end of the world. For example, Elena describes her experience parenting her son with autism as a burden but, at the same time, she feels blessed for having the opportunity to live this experience. Marina represents her experience as an "incessant struggle" but also as a blessing.

The movement between these oppositional aspects is spiral, indicating the process that parents experience, where at times they focus on the negatives and at other times on the positives. The mothers of the group discussion represent this movement, describing how they go up the "mountain" of their parenting experience, with the downhill following and then again repeating the same process. Elena also describes this spiral nature of her parenting experience, involving bending, falling down but getting up and moving on.

Consequently, this study suggests an integrated, complex perspective of the parents' experience, involving quite oppositional aspects of this experience. Additionally, this study presents the parents' experience as a spiral process and not as a still, linear representation. These findings lead me to the conclusion that the parent experiences a multifaceted, complex experience, where at times she may feel devastated but at other times also relieved, she may feel that her life is over but also that she has found a new meaning in her life. It is a dynamic, non-linear process, where parents may feel the burden but experience the hope as well and they move from the bottom to the top of the spiral depending on their psychological state, the changes they experience in their lives or the developmental stages of the child. Consequently, parents are constantly moving along the spiral of their experience, from positive to negative and back again, with some parents experiencing this spiral process and others not.

The importance of my approach is related to the exploration of the parents' experience over time – which is for this study from the time of the diagnosis until the interview – rather than describing aspects of their experience at an appointed time or in a "time frame". This is why I focus on the experience as a process, rather than a single-point and single-aspect experience of parenting a child with developmental disabilities. Parents of children with developmental disabilities are not a homogeneous group, therefore their experience should not be examined in single fixed intervals or emphasizing on specific aspects of their experience, like illustrated in the existing literature. Each parent shares his or her own journey of their experience, of spiral nature or not. As Salvatore and Valsiner claim (2008; p. 11) "each of us can tell our life story – and as it is uniquely ours, it is the reality of the psychological phenomena". Parents' journey is a unique process of their experience of parenting their children with developmental disabilities. My approach on the parents' experience as a process enables a deeper insight into the complexities of the parents' unique journey over time, providing a comprehensive and nuanced understanding of their perspective.

Figure 6.III. The spiral nature of the parents' experience.

6.4.2. The contact with other parents as a 'normalization' coping mechanism

This study suggests that the parents' contact with other parents consists a coping mechanism, which I describe as 'normalization' coping.

The parents' narratives reflect their feeling helpless, loneliness and hopeless. Apart from feeling alone in the whole experience of raising their children and feeling not being understood, parents feel like they don't have adequate support. Discussing about what is helpful, they clearly identify other parents not only as a source of support but as having inspired them. For example, Theodora discusses about her need of approaching and contacting other parents with whom they share the same experience. Demetra presents her contact with another parent as the first hope that opened her eyes. Maria and Marios explain how helpful it was for them to get in touch with other families experiencing the same syndrome with their son. Evangelia focuses on how her feelings towards her son changed following her participation in the parents' discussion group. What is obvious is that parents find relief through their direct contact with other parents, which allows them to develop their understanding regarding their children's condition, to feel safer regarding the future, to feel that they have no reason to feel helpless or hopeless.

This contact might also be mediated, through the representation of the "live" experience of others mediated by cultural elements, such as books, internet search, blogs or else. For example, Christina explains how a book presenting the story of a child with autism, written by a person with autism, rationalized what seemed to be inexplicable for her son, inspiring her a sense of safety. Marios describes how the inspiring stories of other people with disabilities, like Pablo Pineda, helped him to doubt the tragic representation he originally had about people with disabilities and to build a constructive representation instead. Andriana uses the hope story of another father of a child with Down syndrome to inspire herself with positive representations regarding the syndrome.

The contact between parents, as a coping strategy for parents of children with disabilities, has gained substantial attention in the literature due to its profound impact on the parents' emotional well-being. Solomon et al (2001) examine the benefits of parents' support groups, which, firstly, allow developing a sense of control in the outside world, with access to experiential information, increased self-efficacy and the adoption of an active role, instead of the role of the recipient parent – receiving instructions, child's diagnosis or assessment (Beresford, 1994). Additionally, the support between parents helps in developing a sense of belonging to a community, where they feel understood and accepted, they share openly and feel more 'normal'. This effect of contact highlights the therapeutic aspect of parent-to-parent support, such as empathy, catharsis and universality. Finally, the support between parents is also helpful in terms of accomplishing self change, since parents experience increased self-esteem, less guilt and adopting more positive meaning on parenting a child with disability. When most parents report experiencing isolation or stigmatization due to having a child with disability, the between parents' support provide a unique experience of acknowledgement, belonging and feeling valued (Solomon et al, 2001). Bray et al (2017), examining a peer-to-peer parenting support scheme, discuss about the social connection between parents, which, by sharing their feelings and worries, allows the reflection on the positive aspects of their lives while raising a child with disabilities. Accordingly, Shilling et al (2013) conclude that peer support programmes are found beneficial for parents, with their positive effects being related to the possibility of finding a shared social identity, the access to experiential knowledge and the opportunity to get inspired by others.

Wong & Shorey (2022) present parents’ peer support as a valuable social resource for parents of neurodivergent children, contributing to the improvement of the parents’ quality of life, enabling them to provide quality care towards their children. What is helpful in peer support for parents is the emotional as well as the practical support, the recognition and the knowledge obtained. According to Sira et al (2014), a key coping strategy for parents of children with heart defects is seeking support from other parents who have been through similar experiences. Contact with other parents, whether organized through forums or spontaneously, make parents feel more prepared regarding the child's condition, develop greater understanding and feel safe regarding what they have to handle because of their children’s disability (Rempel et al, 2009). Some studies highlight the parents’ preference on the online support groups, as a better way of coping for some parents due to anonymity and availability (Sira et al, 2014). Paster et al (2009) discuss about seeking social support as a usual method of coping for parents of children with disabilities. Overall, parent-to-parent support is described to empower parents by providing emotional and practical support, knowledge and by enabling social inclusion, thus limiting parents’ feeling of social isolation and enhancing their sense of belonging (Chakraborti et al, 2021).

It is obvious, though, that much of the existing literature examines parents support programmes and not spontaneous networking or contact between parents after the parents’ initiative (Chakraborti et al, 2021).

Consequently, the findings of this study confirm the literature regarding the benefits of the contact between parents and their use as a coping mechanism. The parents report gaining valuable experiential knowledge through the shared experiences, which they value a lot. Additionally, they describe seeking support from other parents in terms of emotional and practical help. This kind of emotional support from other parents seems to be therapeutic in nature, where the parent feels relief, limited stress, reduced guilt and probably boosted self-confidence. Most of all, though, the contact with other parents creates a safe place for the parents of children with developmental disabilities, where they experience a sense of belonging to a community. Interestingly enough, the interviewed parents report seeking the contact with other parents on their own initiative, probably due to lack of formal family support networks in the local context.

However, I aim to extend the existing literature by suggesting that the contact with other parents is a ‘normalization’ coping mechanism, which I explain in the following lines.

‘Normalization’ has been illustrated by previous studies as a strategy used by parents in order to cope with their children’s chronic condition (Friedman et al, 2003). According to Rehm & Bradley (2005), ‘normalization’ is not about necessarily fitting into the ‘normal’ standards but about living a ‘normal’ life, despite the possible health conditions, by adopting typical family activities and habits. The findings of the same study focus on the conceptualization of ‘normal’, which is approached as a flexible and not a one-fits-all idea, regularly redefined to accommodate the unique circumstances and experiences of a specific family. Morse et al (2000), studying ventilator-dependent children, focus on the pivotal role of ‘normalization’: the children engage in constant comparisons between their world – where disability is the norm – and the typical world, but primarily use their everyday world as a reference. The children’s longing to fit into their world leads them to identify with the norms from their familiar world, accentuating their similarities while downplaying their differences with people with disabilities. Other studies explore the ‘normalizing’ effect of other coping strategies. For instance, the use of self-enhancing humor as a coping mechanism may allow to ‘normalize’ distress, placing it within a broader context and, thus, diminishing perceived threats, which helps decrease emotional and physiological stress responses (Fritz, 2020).

However, disabilities studies literature criticizes the concept of ‘normalization’ as an idea identified with the medical model of disability and approaching disability as a deficiency that must be corrected in order to ‘normalize’ the person with disability (Haegele & Hodge, 2016). The concept of ableism replaced ‘normalization’, describing more accurately the bias against people with disabilities, reflecting the privilege of one group of people over another group of people based on immutable aspects of the person’s identity (Linton, 1998). Goodley & Runswick-Cole (2016a, 2016b) suggest the concept of ‘dishuman’, which encompasses the recognition of the potential inherent in disability to disrupt and restructure what it means to be human, while at the same time confirming the humanity of people with disabilities. To explain the concept, they present four disability-related factors through the prism of ‘dishuman’: dis/autonomy, dis/independence, dis/ability politics and dis/family, with the latter signifying the desire for 'normal' while embracing the 'non-normative'.

Beyond the terms, though, Landsman (2005) indicates the complexity of the parents' engagement, especially mothers, with disability models. According to her, mothers might identify disability as a societal issue while at the same time pursuing a solution aiming at 'normalizing' their child. Ryan & Runswick-Cole (2008) suggest that since policies and practices are primarily shaped by medical perspectives, it is likely that parents sometimes embrace labels for their children. For example, parents of children with disabilities are found to choose special schools instead of mainstream settings, focusing on protecting the child rather than on emphasizing on the child's learning while protecting themselves as well from the constant reminder of the loss of the 'normal' child (Connor, 1997). According to Runswick-Cole (2008), mothers raising children with disabilities integrate new definitions of 'normal' into their daily routines.

The concept of 'normalization' as used in the literature is different from the way I use it as a 'normalization' coping mechanism for parents. The parents themselves talk about 'normal' and 'non-normal', and respecting their own perspective, I wished to represent that they do it in order to touch what is socially considered as 'normal'. I, therefore, illustrate the parents' perspective of 'normal', who suggest a strong separation between 'normal' and 'non-normal' in several of their narratives. This is highly related with the context in which parents interact and build their representations around 'normal', disability and parenting. In general, I find that parents themselves bring 'normal' as a meaning they interact with.

Consequently, what this study suggests is that the parents of children with disabilities use the contact with other parents as a 'normalization' coping mechanism. The 'normalization' coping mechanisms refer to the processes by which parents of children with disabilities seek to establish a sense of 'normalcy' and routine in their lives, despite the challenges of parenting a child with disabilities. By contacting other parents in similar situations, parents foster a strong sense of belonging into a community, finding relief and feel empowered. In their contact with other parents, parents discuss issues that touch on their daily life, issues that they share with other parents and are part of their routine, which make them feel 'normal'. For example, discussing whether the child has spoken or is making progress from the therapies is a typical discussion between parents of children with developmental disabilities. This contact, as a coping strategy aims to reduce parents' stress, to enhance their emotional well-being and facilitate them to adapt positively to the challenges they face. This between parents contact, as a 'normalization' strategy, makes the parents identify with other parents, reject possible feelings of shame and feel that they are living a typical, ‘normal’ life. By using the world they share with other parents as a reference, the parents achieve to re-define their representation of ‘normal’, conceptualizing their experience as a ‘normal’ one, since it is shared. Within the group, parents feel that their children can participate in life, can play, can talk, can go to school, along with their difficulties. The focus on the ‘normal’ elements of a child's life, i.e. playing or talking, seems to inspire parents with feelings of safety and relief. Apart from that, parents conceptualize their parenting experience as ‘normal’, since it is shared as well. The parents feel ‘normal’ because they belong to a group of people with whom they share the same worries and stresses.

The importance of my approach is related to the emphasis given to the integration of parents into a broader community, that of parents of children with disabilities, promoting their active engagement and participation within the social context. Other coping strategies also help parents, though attaching them on an individual level of coping. Contact with other parents as a ‘normalization’ strategy allows parents to claim a valued position within the wider society, to preserve their social inclusion and to prevent social isolation. Parents, by feeling that they have a ‘normal’ family and they live a ‘normal’ life, while parenting their children with disabilities, participate more actively in the social field, become part of it, give meaning to their existence as part of society and not as justifiably excluded, because of the stigma they may receive at a social level. By reinforcing their sense of ‘normality’ within the in-group – namely parents’ group – parents become empowered, extend this self-concept and potentially feel more prepared to face challenges outside the group, such as stigmatization or exclusion of themselves or their children.

Additionally, the contact with other parents as ‘normalization’ coping, gives parents’ a meaningful way of parenting their children. Parenting a child with disabilities is a human life experience, full of struggles, fights but also laughs and pride. The contact with other parents strengthens this rationale regarding their experience. For example, following a blog that highlights the potential rather than the miserable lives of people with disabilities, might reinforce parents' sense of living their own version of ‘normal’ life and trying to make the most out of it like everyone else does, whether raising a child with disability or not. This helps them construct a productive for them way of parenting but also a functional – for the child and the family – way of being a parent of a child with disabilities.

6.4.3. Hope: moving towards the future

Despite the struggle, the burden, the uncertainty and the fear that parents experience, hope is a central and defining factor in the parents' lives. This study suggests that the parents' hope is generated by the symbolic resources used by the parents.

An interesting finding of the aforementioned stories is that despite the struggle, parents continue to try for the best. Parents might feel fear for their children's future, but they also report hope regarding their children and themselves. Therefore, they hope about something they also feel fear of. Larson has described that as a part of a broader paradox: "maintaining hopefulness for the child's future while being given negative information and battling one's own fears" (Larson, 1998: p. 865). The literature reports these two aspects together, emphasizing on the specific theme of hope and worries about the future (Akerstrom & Nilsson, 2010). According to Kearney and Griffin (2001), parents present feelings of anguish and sorrow but they also express hope and strength, describing a "between joy and sorrow" parenting experience, where conflicting feelings coexist and arise as a result of tensions in the parents' lives. This co-existence of contradictory emotions has been illustrated as the "apparently conflicting stories of sorrow and hope" (Landsman 1998, p. 93).

The parents' fear of the future originates from the child's dependence and the need to care for the child in the long run. Additionally, the worry about the future is also related to the struggle that parents go through, to whether the child will manage to be part of society and in some cases, is about the fear for the unknown, thus related to the child's prognosis.

Despite the fear, parents do express hope, some openly and some others in a more indirect way, with the former discussing at the same time worry and uncertainty. In this case, parents seem to express two sides of the same coin, looking at their children's issues with fear or hope or, sometimes, feeling both. For instance, Yiannis and Marina discuss hope coexisting with uncertainty and fear. The child's developmental progress might also stimulate hope while some other parents express hope indirectly as a fight they must give for their child. Other parents describe the experience of an alternation of emotions, since they adopt an optimistic attitude towards their child, but at the same time they are stressed and afraid for the future.

Hope seems to be vital for parents. Parents experience intense feelings, report that their life is over and represent their children's disability as a burden. But no narrative, even the darkest ones, has the element of resign, as if they have no choice to resign. They need to keep going, they need hope. Hope is, for parents, a prerequisite to effective coping (Jevne, 1991) and adaptation towards the future, since it activates processes of thinking, feeling and acting (Stephenson, 1991). For parents of children with disabilities, hope has been described as a significant predictor of accepting the child’s disability (Juvonen & Leskinen, 1994). However, literature has also emphasized on how rearing a child with disabilities facilitates personal development and growing hopefulness (Behr & Murphy, 1993). This particular parenting experience might gradually and in the long term consist a source of developing qualities such as empathy, love and an overall hopeful perspective (Kausar et al, 2003). Therefore, having a child with disabilities makes parents more hopeful. This hopefulness helps parents cope with their children with disabilities and the challenges of their life. Overall, existing research represents hope as the aspect that keeps parents going, as the endpoint which follows the parents’ process through the aforementioned negative and fearful emotions, as a significant motivation towards the future.

What is not clear from the existing literature is *how do parents manage to hope*, despite the burden, the struggle, the uncertainty and the fear experienced. How the parents’ hope is generated when raising children with developmental disabilities? This study suggests that parents, by practicing various symbolic resources, they manage to negotiate their experience, to cope with the burden, the uncertainty and the struggles of their experience and, eventually, to develop hope towards the future.

Symbolic resources are cultural elements (i.e. books, songs, films) or semiotic systems (i.e. religion) with a personal significant value. According to Zittoun (2007; p. 345), the use of symbolic resources is identified on the way they allow the “turn of a socially shared element into a psychologically relevant resource”, with the person using the symbolic resources achieving a “bridging between their inner world and the socially shared reality”. People use symbolic resources in order to deal with specific psychological needs during transitions, as a means to cope with a rupture (Zittoun, 2004). The use of symbolic resources helps people to process the transition, to cope and to move forward towards the future.

A rupture is a disruption in the regular flow of a person’s life, a determinant change experienced by a person as a discontinuity in the standard course of ordinary life (Zittoun et al, 2003). Ruptures generate imbalance as moving from the previous state of certainty to the unknown, following the rupture, state of uncertainty, which Simão (2003) describes as disquieting experiences. Ruptures are followed by transitions, during which individuals question previous understanding and consider meaning construction (Zittoun, 2006). Exploring the transition to parenthood, Zittoun (2004) analyses the use of symbolic resources by parents, examining the parents' choice of name for their coming children. Focusing on the rupture of immigration, Kadianaki (2010) explores the psychological effects of relocation and the use of symbolic resources by immigrants living in Greece. Thus, transitions offer a window on processes of change at the level of skill acquisition, identity but also meaning construction, ultimately leading to new forms of stability (Kadianaki, 2010). The theory of symbolic resources is further discussed in chapter 3.2.2.

To address the question of how the parents' hope is generated when raising children with developmental disabilities, I approach the child's developmental disability as a rupture for parents. Therefore, raising a child with developmental disability involves a psychological transition for parents. The use of symbolic resources allows parents to cope with this rupture, to create meaning on their children's disability and to move beyond the disruption that this transition created, developing a hopeful perspective towards the future. Particularly, the interviewed parents use the symbolic resources of *religion* and *personal blog* in order to negotiate the rupture caused by the transition of the parenting experience of raising a child with developmental disability.

This study proposes that parents use *religion as a symbolic resource* of dealing with the transition of the experience of their child's disability. Symbolic resources have some functions, they serve a purpose, thus selected by parents for a reason. From the parents' narratives, religion appeared to serve three purposes: to balance the parents' feelings, to connect them with their previous identity and to make them feel stronger.

Some parents report that religion helps them to *balance their feelings*, through releasing stress and becoming more prepared to face the challenges of their parenting experience. Parents seem to practice religion and related rituals as a relief from emotions and as a moral satisfaction that religion seems to offer (see section 6.3.1). This relief comes gradually as religion is exercised. Furthermore, the use of religious resources seems to help parents reduce feelings of uncertainty. Literature has highlighted the role of religion regarding emotions, as a source of hope in the face of stress (Kahoe, 1982), contributing to the regulation of emotions (Griffith et al, 1984).

Another purpose that religion serves is as a *resource* which *connects parents with one of their previous identities*. The parents stated that they were quite religious before having their child with developmental disability, but felt that after the child's diagnosis their faith was strengthened. The ongoing practice of religion in the parents' life trajectory signifies a fixed value that relieves the parent (chapter 6.3.2) and helps them to preserve a strong and constant cultural value in their life, where everything else seems to change. However, this is not the case for all parents, as there were parents who denied their religious identity, like Evangelia who distanced herself from religion (chapter 6.3.2) or Georgia and Demetra who felt angry and betrayed by God (chapter 6.2.1).

Other parents use religion as a symbolic resource in order to *feel stronger and empowered.* Particularly, some parents described adopting important for them religious practices (prayer, kowtow, visiting holy places, repentance) as a great source of blessing, which 'shielded' children with strength and allowed parents to feel stronger. In fact, some parents report that they developed a kind of supernatural power, with the input of religious faith as well in this development.

This research also suggests that the symbolic resource of a *personal blog* is used by parents as a way of negotiating their new parenting experience. Literature supports that parents differ in how they utilize the Internet as a space for seeking support and engaging in debates (Clavering & McLaughlin, 2007). The purpose of the resource of a personal blog in this research, though, is the redefinition of the meaning of disability, specifically Down syndrome, which the interviewed mother's son was diagnosed with. The mother used to hold a completely negative representation of Down syndrome until she discovered this blog, which, according to her, focus on the bright side of the syndrome's experience. Through the hope story of a father of another child with Down syndrome, which the blog illustrates, the mother constructs new meaning about her child's disability, about her maternal role but also about the family of a child with Down syndrome. This blog made the mother feel more hopeful and optimistic, mainly because the mother's meaning-making on her child's disability allowed her to realize that children with disabilities, including her son, may have a life worth-living and are not rejected by default.

Apart from negotiating the transition and coping with the rupture, symbolic resources impact on the individuals' psychological growth (Zittoun, 2006). The aim of this personal development is to allow space for self-consistency and continuity (Kadianaki, 2010). Zittoun (2004) describes transitions as occasions for self-development, in terms of developing new skills and understanding about life-challenging situations. Specifically, parents argue that their experience of parenting their children has made them stronger persons since they feel that nothing affects them anymore, suggesting a sense of personal growth. Andriana discusses about their children's disability as something they need as parents to learn to live with, like a personal success that they gradually attempt and accomplish as parents, as an achievement of future personal development. Thus, the symbolic resources used by parents seem to lead to potential personal development, since they aim to establish a new form of stability and guide themselves towards the future.

According to Zittoun (2006), the use of symbolic resources helps people to process the transitions they experience in order to redefine and reposition themselves and to construct meaning about their new experiences following a transition. Accordingly, this study suggests that parents of children with developmental disabilities engage with various symbolic resources, which allow them to negotiate their experience of raising their children with disabilities, to cope with the struggles of their experience, to move towards the future and potentially to achieve self-development.

This approach of the use of symbolic resources by parents of children with developmental disabilities is an important input to literature. Symbolic resources, such as religion and blogs, provide parents with a framework to make sense of their experience parenting their children with disabilities and to manage this psychological transition in their lives. For parents, these specific symbolic resources serve as tools to help parents cope, redefine their roles and find meaning in their experiences. The new point emphasized here is the role of symbolic resources when used by parents raising children with developmental disabilities. By doing so, they are better equipped to handle the challenges they face, to find ways to cope and to move forward with a sense of purpose. Additionally, these symbolic resources can facilitate their personal growth and development, enabling them to adapt and thrive despite the difficulties they encounter due to their children disabilities in the particular local context. The significance of my approach lies in highlighting how specific symbolic resources are employed by parents in coping with raising their children with developmental disabilities. It emphasizes the importance of these resources in enabling parents to navigate their parenting experience, to redefine their parenting roles and ultimately to achieve resilience and personal development.

Chapter 7: Parents' self-related issues

This chapter aims to examine the parents' self-related issues throughout their journey of parenting children with developmental disabilities. The parental journey for the purpose of this study embraces a long-term perspective, since it accounts from the time of the child's diagnosis until the period of the interviews and the discussion groups, which differed from parent to parent according to the age of the child when diagnosed.

The parental self-issues are greatly impacted, since the child-parent relationship and consequently the fulfillment of the maternal or paternal role are influenced by the child's disability. Additionally, the child's increased needs for care introduce parents in a multiple caring role, including basic need care, education, therapies and more. Through this course of parenting a child with developmental difficulties, the parent changes significantly and seems to experience some losses in certain aspects of his or her self, such as negligence of self and loss of their social and work life. However, parents seem to cope with the self and parental challenges, developing a new aspect of themselves through sharing their experience and building solidarity with other parents of children with developmental disabilities.

7.1. The parental role

The parental role when raising a child with developmental disabilities involves several challenges. On the one hand, the emotional bond of the parent with the child is greatly affected by the conditions created from the child's diagnosis, mainly due to the child's difficulty to communicate. On the other hand, the parent is burdened with an increased caring role, due to the multiple and specialized care needs of the child.

7.1.1. The parent-child emotional bond

The parent-child relationship is different than when raising a child without disabilities, with several obstacles into fulfilling the maternal or the paternal role. The mother in the following narrative exemplifies this particular relationship:

C. Or, for example, the child being unable to share their feelings with their mother. Do you realize what this means?
ED. Mmm.
C. Your daughter being unable to tell you "I love you, mum". That is …
ED. Yes.
C. … it is disheartening to think, as a mum. And having to … to, to find ways other than what nature intended to … to, to use in order to … to communicate the way you feel. Namely, speech, touch. And all this, you have to … A hug. To find another way to express feeling. And I consider this extremely difficulty.

Christina, mother of a 7-year-old child diagnosed with autism

Christina describes how the emotional sharing and interaction between the child and the mother is not at all given but almost impossible. The absence of this vital interaction essentially results in the invalidation of the maternal role, which the mother represents as tragic. The mother also attempts to generalize the issue, addressing to the researcher herself and by suggesting that this lack of interaction is tragic for every mother. Looking for other ways of communication is difficult but required in this case.

The difficulty of communicating with the child is an issue that often concerns parents, as reported by the father in the following extract:

A. For example, with Philippos, I take a step back sometimes and … I observe him, I try to understand what goes through his mind, what it is that he sees, how he sees it …
ED. Yes, yes, yes.
A. How he understands it, how he interprets it. I try to walk in his own shoes more, instead of being judgmental and point the finger at him (…) I try to understand him and always (emphasized) try to approach him differently than others do, Philippos and I have a different way of communicating.
ED. Yes.
A. We have a different … umm I know, he knows, I know that he knows that I love him, and I know (emphasized) that he loves me. There were times when he told me. And that was a tremendous-tremendous surprise, coming back home at night, going to kiss him, and hearing him say "dad, I love you". It's something that you know these children never say.
ED. Yes, yes.

A. … they never say 'I love you' because they don't understand it, it is too abstract. Children like Philippos are literal. If you tell them "guys, it's raining cats and dogs outside", they will go look for cats and dogs, find where they are.

(…)

A. It's, it's the daily bonus. I mean, this thing, him smiling from ear to ear. And I am taken aback and say "what did my ears hear? I mean … did my child really say this?" "Am I hearing things?"

Alexandros, father of a 6-year-old child diagnosed with autism

The father in this extract emphasizes how the communication but especially the understanding of his child with autism is not at all obvious but requires extra effort. The parent is often in an unknown direction, unable to understand what his child is thinking, feeling or wanting. The absence of expression of emotion and of manifestation of love from the child is common and may generate problems in fulfilling the parental role. It is like a piece of the relationship has being removed.

The emotional challenges of the parent-child relationship impact deeply the way the parent feels towards the child:

G. You do love the baby, you adore it, but someone who doesn't know … might not even understand why you love them. Why do you love that baby since it has the [issue]. Yet you love it, you don't know why, but you love it (gentle smile). You love it more than you ever loved anything before, if that's possible.

Georgia, mother of a 5-year-old child diagnosed with autism

Georgia, mother of a non-verbal child with autism, reflects on the interaction with her child as a source of sharing emotion between them. Since the child does not express emotion, the mother finds it difficult to approach or even express her love to the child, to come close with her child. What the mother describes is an internal struggle of experiencing strong barriers, related to the child's difficulties due to its diagnosis, blocking her from getting emotionally involved with her child.

The doubt here seems to be related with the love towards the child with disabilities, as a non-normal and not ideal child (*why do you love that baby since it has the [issue]*). But it might also be associated with the content of the parental relationship and the limited externalization of emotion from the child, which makes it an emotional interaction with no return of the emotion. This lack of emotional interaction impacts the parent-child relationship, a supposedly two-way interaction, with the parents experiencing mixed feelings regarding this relationship. The severity of the disability, as well, especially regarding the dimension of communication, seems to play a decisive role in the emotional parent-child interaction.

7.1.2. The parents' multiple caring role

A major part of the parental role when raising children with developmental disabilities is the parents' caring role. Caring for children with disabilities involves multiple needs, which denotes an increased caring load and makes the parenting role more complicated. The mother in the following extract exemplifies this advanced type of care:

D. … in our case, because from when, when … the baby was a few months-old umm the child umm … they stressed us out with "we need to keep checking her curves", "we need to keep checking her weight", umm … "whether she eats enough", "whether she drinks enough", they even, they even suggested getting a gastrostomy because she wasn't drinking much water. (…) And they were telling me, "let her get hungry", "give her big pieces of food, to, to force her to eat on her own". Or "don't feed her". (…) I thought that she wouldn't eat as much on her own as she would have if I fed her, so I didn't dare to do it. (…) The occupational therapist was the one who convinced me to dare to do it. Who specifically told me that (…) the main, the main use of a person's hands is for eating.
(…) Well, she also had therapies done, she had speech therapy sessions even as an infant. (…) really intense speech therapy sessions in the last few years. We do 4 different types of speech therapy. Umm I mean, umm the hours that … Natasha works … she is making a remarkable effort, she is always working on …
(…)
D. I didn't umm I didn't have … I didn't have, umm I became a parent for the first time, I knew that I needed to take care of my child. (…) And yes, the thing is that … Okay, one issue is solved, then there's another one shortly after. They, they never end. (…) Umm effort, effort, effort. It requires a constant effort.
(…)
ED. Where do you draw strength or energy from to cope with all this?

D. From my own child (eyes water, weeps). That … umm she basically relies on me. That she is completely …she is completely reliant on me, for her therapies, for her to grow up, for her care, for everything. (…)
ED. What does it mean to you that Natasha has this disorder?
D. Umm that … my life … will maybe have an extra degree of difficulty in comparison to others. (…) The fact that it requires so much strength, persistence, a huge effort … not only when it comes to the child's issues. I mean as person as well, it requires … so much mental strength.

Demetra, mother of a 6-year-old child diagnosed with Alpha syndrome[39]

The mother describes the various issues she had to deal with as a parent for her daughter. Already from infancy, there had to be special care in everyday matters such as food. Then, the mother had to arrange and possibly take part in her daughter's therapies, which were intensive and specialized. There is a constant rotation of issues that need care from the mother, either practical or complementary care, resulting in the need for continuous effort, both on the part of the child and on the part of the parent. The care described by the mother involves other, different than usual pieces of care, within very structured contexts. Additionally, the mother is found in need to develop several special skills – namely to be flexible and constantly alert, searching for solutions and continuously trying – and a level of mental strength to respond to this demanding multiple caring role. Given the amount of such parental care due to the increased care needs, within such conditions, it seems that the maternal role cannot be experienced freely or effortlessly but only within strict contexts of complicate, demanding and specialized care.

Several parents confirm the complexity of the caring role and the exhaustion it entails. Marina reports the burden of the numerous things she has to think about and take care of *(… you have to take care of everything, go to doctors, go to therapists, go to schools, go (…) You have all these things to do from the time you get home until night time, there are thousands, hundreds of things that you have to think about, and also do, and you're trying to handle the situation. Going home and having all these issues, I don't know, umm it's difficult, yes).* Discussing the outcome of the group sessions, participating mothers are debating another name for the group, which is indicative of the effort they put in their parenting role (*E. Superwoman team! [said in English] (…) Umm … there are so many things, I think, that we have to do during the day, so many things to think about. An. Said, we should*

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[39] Alpha syndrome is a pseudonym of a rare syndrome.

be creative, we have to think of new things, let’s say, to … Umm I think, okay. Umm there are more … demands than usual).

What several parents of children with developmental disabilities report is that their caring role also includes another – totally essential – educative role. The mother in the following narrative exemplifies this consideration:

An. I think, at least with what has happened to me, umm I feel that “yes, I am Gregoris’ mum, yes, this issue exists”, after what has happened to me, I had to study more, find some other solutions, to … you instantly become more creative and you're the one who decides … (…) Umm it is extremely important. It’s … it’s something that we will face. We will be ready, don’t be afraid of it. I talked about this concern yesterday, a concern that I have as well: to not be afraid of it, to be ready. For the future. (…) for independence and functionality, our children have an aptitude for things that other children don't have, or they learn in a different way. So what we must do is guide them, it’s not our job but we do that as well, we act like teachers for our kids, for their learning and anything they … For things to be easier for them after we have a good understanding of the situation.

Anastasia (group discussion)

Anastasia, mother of a child with autism, reflects on the need to get as much informed in order to be able to find solutions for her son. This necessity seems to be related to her worry about the child's future. Although she acknowledges that it is not her job, she nevertheless emphasizes the importance of this knowledge and education so that she is able to prepare her child for the future.

Another interesting attribute of the caring role, is the gender differences between mothers and fathers. It turns out that mothers undertake more of the child’s caring needs. The father in the next extract describes this difference:

M. Of course, I have to tell you something. Umm it makes a difference who you hear it from. More specifically, the special educator, or the speech therapist we take Antonis to may be critical, or this, or that.
ED. Ah I see. Yes.

M. Okay? Who may tell us, and Christina has done so many times as well, but she is right, and so am I. Okay? When you are constantly scolded, that as a parent you don't do this, you don't do that or … Okay, it gets tiring. And it gets tiring and it drains you umm … because obviously, as a parent of a child with particular characteristics, or of a child who is on the autism spectrum umm hehe (smiles) you do more things hehe (chuckle) eventually. That's what I think. Okay? Or there is one more thing to think about …
E. Hmm.
D. Which is really important, because aside from the practical aspect of it, one person informing … (unintelligible) the other, and so on. But you also have to think of things … umm. Christina especially, umm has taken on a greater … burden, umm burden. Okay? Much greater than I have.
E. Hmm.
D. Okay? And that's why maybe she gets tired even more easily than me. Okay? Umm … why? Because she takes care of so much more. Okay?
Marcos, father of a 7-year-old child diagnosed with autism

Marcos, while discussing the comments they occasionally receive as parents from the child's therapists, he acknowledges that the mother takes on more of the burden of caring for their child. Unlike Anastasia in the previous narrative (*A. ... not in our own business but let's do it as well*), though, parents here seem to obligingly get involved in the educative or therapeutic plan of the child. Both parents, however, adopt an educative role, which in combination with the comments of the therapists is proved to be tiring and possibly exhausting. What is also interesting in this narrative is how the voice of the other, namely the therapist or the educator, is introduced to the father, about the parents' insufficient effort, placing a big burden especially to the mother. Replying to this, the father instead highlights the extra effort needed in the care of a child with autism, compared to the care provided by parents of children without autism.

In other families, the sharing of childcare is much more distinct, with the mother taking full care of the child with disability. Elena in the following narrative exemplifies very well this discrepancy between mothers and fathers:

E. We had reached a point where I had taken over all the responsibility for the children. Umm and Lambros just kept living his life as it had been. (…) Even in conversations I took part in, like today for example, this, what happened at school. That, I was concerned about what to do with Stephanos' school, for him to go to a private school …

ED. Yes.
E. His answer was, “Elena, do whatever you consider right”.
ED. Ah okay. Therefore …
E. Which is good. But it’s also bad, because if some decision didn’t prove to be right, he could tell me, “well, it was your decision”.
ED. Yes, yes. Umm there was a … how do I say this? Assignment, that you are the one responsible.

Elena, mother of a 10-year-old child diagnosed with autism

The mother describes how she fully undertook the care of the children, compared to their father who continued his life, with no particular changes. In fact, she explains that in addition to the practical providing of care, she also felt that she lacked the sharing of responsibility, which was also 100 % on her, since their father didn’t choose to take this responsibility.

7.1.3. Summary

The parental role when raising a child with developmental disabilities is firstly significantly related to the difficulty of the emotional bond between parent and child. The lack of communication and the emotional interaction between parent and child is a challenge, requiring extra effort. Sometimes, parents even wonder about their feelings towards the child, loving the child but not knowing why. Another feature of their parenting is the difficulty to feel satisfaction from their role as parents of children with developmental disabilities.

Another vital part of the parental role is the increased caring load that parents need to undertake. Caring is most of the times a complex and demanding experience, involving dealing with basic, therapeutic, educational or other needs of the child. Those needs of the child are placing a strict context in the child-parent relationship, due to the constant effort and the necessity to satisfy these needs. For parents of children with developmental disabilities, a significant aspect of caring is about adopting an educative role: parents are actively involved in their children’s education, therapies and developmental progress. Parents usually respond to this demanding multiple care role by developing additional parental skills. Lastly, several parents also report the gender differences between fathers and mothers, with the latter to take on a greater burden of care.

7.2. Loss of self

The diagnosis of one's child with a disability may signify a big change in the parents' view of themselves in the world, namely in their identity. Parenting a child with developmental disabilities seems to make parents feel losing their sense of self. The loss is often related to their self and/or gender identity, their social life and their working identity.

7.2.1. Loss of parents' sense of self beyond the parental role

Parents report neglecting their selves since the diagnosis of their child, with their total focus being on the child's needs. The mother in the following narrative exemplifies this loss:

G. No, after the diagnosis is … I completely neglected … I stopped being not only a woman, I stopped being a person. Umm I had completely neglected Georgia … (bitter smile) …
ED. What … would you like to tell me more about this?
G. My only concern was taking him to his therapy sessions, for him to be there on time, at his therapies, to be … my only concern was doing some things at home …
ED. Exercises and stuff…?
G. Yes, yes. I had no time…
ED. So, you weren't interested in doing anything else?
G. Yes, yes. (…) I had forgotten everything.
Georgia, mother of a 5-year-old child diagnosed with autism

Georgia, mother of a child with autism, explains how she totally neglected herself after the child's diagnosis. The focus was exclusively on the child and his increased needs, namely therapies, home education and more, that nothing else even mattered. This is how she stopped feeling not only a woman but generally a human being. What the mother describes is as if she no longer existed as an autonomous identity, as if Georgia as a person disappeared and the sole reason for her existence was to satisfy the child's needs.

Other parents describe, as well, a devastating loss of self while parenting their child with developmental disabilities. The mother in the next extract reflects on this loss:

M. No, everything changed. Nothing was the same anymore (laughter) Everything was flattened!
ED. Yes. What … what were the changes?
M. The changes. The changes were that … mmm … it was having to run around. For therapies …
ED. The therapies, running around, evaluations …
M. Oh, you can't even imagine! (…) Running around. Your private life, you have no private life. Your social life has become non-existent. I have now started … now that Maria's situation is a little more stable, I started going for coffee with a friend of mine. Just to sit at the cafeteria for a couple of hours, or even for one hour. Just to be able to relax as a normal human being.
ED. Yes. Yes, yes.
M. I have now started, after … after nine years. (…) Eleni, just think that I am 38. During my thirties, I should have been able to enjoy life, like other women do. Going out, going for a coffee, going to the sea, going shopping, going … feeling good. Not feeling anxious, feeling … I have, I have missed out on this decade. You see? I missed out … I feel like I have missed out on an entire decade.
Marina, mother of a 9-year-old child diagnosed with developmental disabilities

Marina discusses how her life tremendously changed after her daughter's diagnosis. The change is directly related to how the parent was constantly busy with the child's therapies and developmental progress. This goal required absolute dedication from the mother, resulting in the total neglect of her other roles as a person, namely personal or social life, self-care or enjoying life. This enormous focus on the child makes the mother feel that she lost not only her other aspects of self apart the parental but also a big part of her life. In fact, the mother discusses this loss by comparing her life to that of other women in her age, reflecting essentially about the ideal self she would have had, without the condition of her child's disability.

Another loss that parents report experiencing in relation to themselves is the limitation of self-care. The mother in the following narrative exemplifies this consideration:

E. Look. As Elena, I have stopped looking after myself.
(…)
ED. And … when you say you have stopped looking after yourself, were there any things that you stopped doing?

E. Yes. I had umm my hobbies, working out, socializing … I used to pay more attention to my appearance. Umm I don’t bother, umm they have all gone now. Disappeared.
ED. Mmm.
E. I used to cook a lot at home, I didn’t have the strength anymore, I just cooked the most basic foods. Umm I didn’t have the strength.
Elena, mother of a 10-year-old child diagnosed with autism

Elena, mother of a child with autism, highlights the loss of self-care. Indicatively, the mother uses the word lost to describe the activities she gave up when she had to focus entirely on her son with autism. Both Marina in the previous extract as well as Elena in this one report losing aspects of their lives which are closely related with their feminine but also their adult yet young identity: taking care of their appearance, going to the gym, socializing, having hobbies, home cooking, shopping, having fun and going out. Elena does not fail to mention apart from time, tiredness as a major factor for quitting her personal identities.

It is interesting how parents report losing a part of themselves which they enjoyed. Vasilis, father of a girl in the spectrum of autism, describes how he lost his personal time, which was devoted to things he loved doing (*V. You used to have time for yourself … now you spend that time researching about your baby. Basically, you have no private time anymore. (…) Umm I liked creating things. Not creating, to … I liked cars (…) As a hobby. I liked … getting myself to think, let’s say, if I changed this in my engine, what would happen? (…) Well. There’s no time, hehe (chuckle).* No time at all). The mothers in the group discussion reflect on how their personal needs are not at all and will never be a priority (*E. I don’t think our own needs will ever be met. That’s what I think. There are so many things that we have to do, our battle is so tough that we forget about our own needs … we leave them behind, they are not our priority. I. We leave them behind, it’s impossible. E. Yes… You just don’t have the time*).

7.2.2. Loss of parents’ social life

Another loss parents regularly report is the loss of their social life. Parents limit or completely stop socializing from the point of the child's diagnosis onwards. The mother in the next narrative exemplifies this loss:

M. … the truth is that in the beginning, I told my friends, but I didn't talk much to them, because I was running around to save my baby. Specifically, in the first 3-4 years, I didn't … I didn't have … I was focused on my baby. I would talk to my friends on the phone once every six months. It wasn't, let's say … It was probably once a year. I mean, I became isolated, I had no … it was just me and the baby.

Marina, mother of a 9-year-old child diagnosed with developmental disabilities

The mother reports losing completely her social life for the first years after her daughter's diagnosis. It is indicative how she describes the limitation of her social life, as if she was completely excluded from the world and only the mother and the child existed.

The special but also exclusive bond between mother and child, and how this bond impacts on the mother's social life, is reported by other mothers as well:

ED. Umm I want to ask you, after the diagnosis, how did the family's routine change?
E. Well, the routine exists, um because I couldn't just leave Stephanos with just anyone. We also were, I was anxious about the fact that he was unable to speak.
ED. Ah. Yes.
E. Umm so I couldn't, I couldn't leave him with the housemaid on days that I didn't have to. Because I had to leave him to go to work. Well, there were days when I was highly charged, because I felt that I should leave him with others only when I really had to. So I had to do everything with Stephanos when he was younger. Umm always with him, even placed him in the shopping cart in the supermarket, everything together, everything!
ED. Mmm. Mhm.
E. Umm …umm and that's how the family is affected, with what I'm telling you umm … we became disorganized. It wasn't easy … You couldn't easily go visit other people, or have them come over. Because Lambros had to figure out, we, we both had to figure out how our child works.
ED. Umm for you, as Elena, are there things that you stopped doing after the diagnosis?
E. Yes. (…) umm I lost a lot of friends, because I couldn't follow the schedule. By 'I lost', I mean I no longer have any contact with people I used to. Umm there were many people that told me, "come on, do you want to go for a coffee?" I couldn't just leave Stephanos, since Lambros was not there.
ED. Yes, yes.
E. We had this other issue with Stephanos too, that because he was so attached to me, he could not accept it when I had to leave the house. Not even if he would stay with Lambros.

Umm there were times when I had to leave, umm and I left through the window. I climbed through the window to leave, just so he couldn't realize that …
ED. Seriously?
E. Umm chaos erupted whenever I would leave the house, he was knocking on doors, windows, he was kicking. Umm if I left through the window while he was watching TV, umm okay, he reacted a little, but it wasn't as intense.

Elena, mother of a 10-year-old child diagnosed with autism

Elena, mother of a non-verbal child with autism, while discussing the difficulties of childcare when she was not available (i.e. during her working hours), she describes the impasse she felt as caring for the child was solely her responsibility. She overall presents the objective difficulties related to the child's functionality and presenting problems, resulting in her subsequent continuous engagement with the child. Not having an alternative, she is necessarily burdened with all the care of the child, to the point where child and mother become inseparatable. This means restricting the mother to the exclusive care of the child, adapting the social life of the family to the child's functionality, but also excluding the mother from any kind of social activity.

The mother indirectly raises the problem of alternative care for children with disabilities, so that the parent can take a break or meet his/her own needs (self-care, socializing, etc.). In the case of children without disabilities, this role is largely adopted by the extended family (grandparents). Lack of home or supplementary care services for people with disabilities but also lack of family supportive services is a major deficit in the social services policy provided in Cyprus.

Most parents emphasize that the loss of their social life is not a matter of choice and it is not possible to maintain a social life when parenting a child with developmental disabilities. The mother in the next narrative argues on this idea:

E. Umm I have pretty much lost them too. They don't … they don't exist. You drift away. I mean … I try to think … For example, I had a great friend, but she's in Limassol, she's too far away. But even while she was in Nicosia, we only got to meet a few times.

Eleftheria, mother of an 11-year-old child diagnosed with autism

Apart from not having the time or the strength, the necessity to follow the child's developmental needs does not allow for the parent space to socialize. Eleftheria uses the word alienation to describe her isolation from her previous – small but existing – social circle, namely from her friends.

Invitation for kids' parties is a topic often raised by parents. Parents initially discuss this as a sign of their child's exclusion, who cannot socialize properly or equally with other children of typical development. However, children's parties seem to be a way of socializing for the parents themselves (*A. Well … as a parent, you feel good when you get to go somewhere where you can talk with other parents, to socialize somehow*). Yet, some other parents choose themselves not to go to parties, because of the child's difficulties (*E. Or at birthday parties, I never dared to go. Even though I do find the birthday invitations in Sophia's bag … I think to myself "what will happen when I go there? The rest of the parents will be sitting, relaxing, having a coffee. I will have to run after Sophia." So even If I go, I wouldn't be able to meet the other parents and socialize … and my child won't socialize either*).

Some parents present a different picture of their social isolation, like they really need this time on their own:

E. That's why I think I started isolating myself more, umm I get along with myself very well in the past few years, do you know how good of a time I have by myself? Umm …
ED. Hehe (chuckle).
E. I don't want any contact with … sometimes it's … (…) Yes. For example, sometimes you may go out and hear something like … pff (sighs) 'I've lost the meaning'. Umm … you … you feel somewhat depressed, and you say to yourself 'I won't bother, I'll stay at home and have a better time'.
ED. Heh (smiles).
E. And I really have learned how to have a good time. On my own as well. I get along with myself very well in the past few years. (…) I am bored. Bored. People make me feel bored. Bored. People make me feel bored.

Elena, mother of a 10-year-old child diagnosed with autism

The mother seems to rationalize the loss of her social life by suggesting that she has a better time by herself. However, her words convey a sense of defensiveness or a kind of emotional impasse, perhaps following disappointments or hurts she experienced within her social life. Her words represent how hard it is to feel excluded or to feel that your child is excluded. Possibly because of the second one, the mother chooses to exclude herself as well.

However, it is quite interesting that the loss of social life is not the same between mothers and fathers:

E. Umm it's knowing that everything regarding your, your children depends on you. For example, Lambros is at work now. He will return at 9.
ED. Yes.
E. Umm even the school he had, umm sometimes he would go on trips with the school, for training, things of that nature. Which was also his hobby. I didn't have that.
ED. Yes.
E. Go to the beach for three hours with a friend.
ED. Yes, yes.
E. Never! Never!
ED. So you believe that Lambros didn't have to make many changes. He carried on with a … more normal routine.
E. More normal.
ED. Yes.
E. But umm … you know, when both people are highly charged, you may have other problems. So, you think that it's better to leave each other alone.

Elena, mother of a 10-year-old child diagnosed with autism

According to the mother, the loss of her social life was completely unequal, with the mother entirely sacrificing her social identity compared to the father who continued a "normal" course of social life, with hobbies and leisure activities. This imbalance is solely related to the full burden of the child's care, undertaken by the mother. However, the mother rationalizes this inequality, as a prevention from other – possibly between the couple – problems.

7.2.3. Loss of parents' working role

A critical aspect of the parents' self is their employment. Frequently, parents' working status is directly or indirectly affected by the diagnosis of their child with a developmental disability. Some parents discuss the loss of their working role.

Indicatively, the father in the next narrative had to change his work since his daughter diagnosis with autism:

ED. How did your routine change, the daily life of the family, after the diagnosis?
D. Umm (faint smile) we became even more isolated. And we had to go everywhere, from doctors, to lessons and … therapies. We were just following Sophia's pace.
(…)
D. Well, look. I traveled, I used to travel until 2014, but I had to stay after that because there was no way Eleftheria could carry the whole burden on her own.
ED. Mhm.
D. So I found a job here and I stayed. So that's when we started having a flow (…) we reached a… balance then, when Sophia was 4-5 years old. (…) Well yes, I quit my job on the cruise ship. And I came here. What could I do? I had no other choice.
ED. Yes. Yes, yes.
D. You have to, you have to keep re-evaluating your life in order to have priorities (emphasized).
ED. Yes.
D. What is the priority today? This one. That's what you have to do. What else can you do? You can't do anything else. You can't do what you want to do either. Like we said, when you have this issue, you now rely on what Sophia wants.
Demetris, father of an 11-year-old child diagnosed with autism

Demetris describes how he sacrificed his chosen and desired work because he had to prioritize the needs of his daughter with autism. The father emphasizes that precisely because of the child's diagnosis, there is no choice, nor does the parent's wish for his employment course matter: taking care of the child and her needs is the one and only priority. It is interesting, however, that the child's care is represented as both parents' responsibility.

On the contrary, in other families, the responsibility of care is unbalanced, with the working status of one of the two parents being directly affected:

E. We went through a lot (emphasized) umm of stages, regarding this issue. (…) Umm because Lambros just kept living his life as it was before. My job now, if I want to … umm. When Stephanos was born, umm he wanted to start his own Martial Arts school, because *he was into martial arts. And that’s when the tension between us started to build, because at that time, I was also working and I said that ‘you have a job and you’re doing fine at your job. You starting a Martial Arts school and coming home at 10 at night, means that I have to carry the entire burden’, because I was going to work, and had to leave my kids with the foreign house maid. Who worked at our house. Umm … it was really emotionally draining! But he had that too, he wanted to have his school.*

ED. Mmm.

(…)

E. Umm eventually after so much (emphasized) we, we went through. We were yelling at each other, fighting, I won’t say that everything was ideal. Yelling, fighting … aah.

ED. Yes.

E. Well, I reached a point where I decided that this is it. Umm I can't change things. So umm I take things as they are, and I move on, umm I do what I have to do. So umm I had taken over the entire burden of the children. (…) Yes. Umm after the company I worked for closed down, I had the opportunity to stay at home, and he also told me “with the issues we have at home, you can't go to work. Stay at home, with the kids, and I will be responsible for the finances …”

ED. Mhm.

E. “… of the family”. I admit that I didn’t have to carry the burden of going to work as well, even though we needed it, but, but, but I didn’t have to. So, he gave me the chance, he told me, he gave me the opportunity to focus on, at 100%, umm on my children. And not having to worry about the financial aspect of things.

ED. Yes.

E. Which is exactly what happened.

Elena, mother of a 10-year-old child diagnosed with autism

Elena discusses how she ended up quitting her working status after her son’s diagnosis with autism. She used to be a working mother, yet quite in charge of taking care of the children. Her narrative emphasizes on the conflict between her and her husband as he, according to her, was not willing to deviate from his own priorities, namely his job and hobby. It is interesting how the care of the children is almost automatically assigned to the mother, who appears not to have been asked about her needs, namely sharing the responsibility of the children’s care or selecting her course of employment. Of course, feeling the responsibility of caring for the children, the mother seems to have experienced a deadlock, ending up undertaking the complete care of the children and choosing to stop working. From the mother’s account, it seems that the decision was made by the husband, however she presents this choice as a solution, as a “chance” given by her husband, to the burden of care. The child's diagnosis with autism seems to play a critical role to this decision (*"with the issues we have at home, you can't go to work"*).

Similarly to Elena, for some mothers, childcare of a child with disabilities seems to be the main reason of quitting their working status. Irene explains how she used to work but this is not the case anymore (*ED. You're not working now, but did you work in the past? I. Well, (sighs) before I got married.* Ah umm when the twins were born and we realized that Nayia has an issue, I couldn't, I couldn't go to work). Giving up their working status is not about a choice, it is a matter of impossibility, since it's impossible to take care of a child with disability and work in parallel. Besides, this gender imbalance in the working identity of parents of children with disabilities, with women almost unquestionably leaving their jobs, is commonly acknowledged, with almost the same rationale.

The father in the following excerpt explains, as well, his similar version about his wife's loss of working role:

M. Look, they really changed the daily life of the family[40]*. Namely, since Christos was born with Down syndrome and he had to go to lessons or therapies, whatever you call them. That means that someone has to go with him. That means that his mum will never go to work. And that she has to stay home with him now.*

Marios, father of a 6-year-old child diagnosed with Down syndrome

Marios also describes how it was impossible for his wife to continue working, after the birth of their child, which coincided with his diagnosis with Down syndrome.

At the bottom of this difference between mothers and fathers is a common gender stereotype, still quite strong in the Cypriot context, according to which the mother is the nurturer and caretaker of the children and the father's role is to work and financially support the family.

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[40] Meaning the child's therapies changed the family's routine.

7.2.4. Summary

A frequent discussion among parents is their sense of losing themselves while parenting their children with developmental disabilities. This loss is firstly related to neglecting oneself, with the parents' total engagement with their children's increased needs. Self-care, personal time, rest or hobbies seem to be left outside when the parents are only focused on the child's needs. Another great loss that parents experience is the loss of their social life, since they are either completely excluded from any socialization or take enough time to return to a socially active status. Lastly, parents describe losing their working identity, with some of them having their jobs affected but others totally quitting their working status in order to completely focus on the child's needs. Interestingly, the loss of social life and work status is not the same between mothers and fathers of children with developmental disabilities, with mothers being much more affected than fathers.

7.3. Coping with the parental and self challenges

Parents experience several challenges on their parenting role when raising children with developmental disabilities. The challenges in the parental role mainly concern the parent-child relationship and the increased burden of care. At the same time, parents experience some losses, regarding their sense of self, their social life and their working role.

What this chapter explores is the ways that parents find in order to cope with these challenges. First of all, parents mention the importance of social acceptance, from the close and wider social environment. Another element that helps parents in their parenting role is helping and sharing with other parents. Finally, parents seem to experience a kind of transformation, where they gradually adapt to the new circumstances.

7.3.1. Social acceptance

For some parents, sharing their experience of parenting a child with developmental disabilities seems very important to them. Feeling socially accepted, unconditionally of their children's condition, seems to determinate their experience of being a parent of a child with disabilities. The mother in the following narrative exemplifies this consideration:

A. I don't want any consolation. I just want to cry. And I experienced it for entire days. I told my sister, "I want to tell you something, I am gonna cry". And I did that with three people close to me that day. I mean, I wasn't feeling well the rest of the week. It bothered me tremendously.
(…)
A. I usually receive consolation, because they are also mothers who experience something similar, they are co-workers, who have a great approach (…) Parents don't need pity.
ED. Yes.
A. They want friends. Then want birthday party invitations.
ED. So they don't feel lonely.
A. They don't want to feel lonely. They want acceptance.

Antonia, mother of a 6-year-old child diagnosed with autism

Antonia, while discussing her son's exclusion from the summer school, she explains how much she needed to share this incident with significant others in her life. Her focus is to be able to share her problem, without receiving criticism, something necessary, according to her, for all parents of children with developmental disabilities. The others' simple daily movements, like party invitations, may help parents feel accepted.

The mother in the following extract has a different memory of social acceptance:

A. But okay, later on … I remember that the entire family came to my home later on.
ED. I see.
A. Specifically, my siblings … umm …
ED. And you think that this happened for this reason.
A. Yes. My mum, my dad, my siblings, my nephews and nieces. They all gathered at my home every day.
ED. Did this help you?
A. I think so. Because I somewhat felt that I wasn't alone.
ED. Mmm.
A. Or that for them to be here, it means that they care.
ED. Did you like discussing about it? Sharing it?
A. Umm … I don't think umm … we didn't discuss anything. It just umm …
ED. About the issue, they were just there.

A. Yes, they were just there. And umm … I think that was more … more important for me. Not discussing it, since, okay, the baby has Down syndrome, but we still love him, we will care for him, we will play with him …

Andriana, mother of an 8-year-old child diagnosed with Down syndrome

The mother, while describing the presence of significant others in the first days of her child's birth – which coincided with the child's diagnosis – emphasizes on the importance of not feeling alone and on experiencing social acceptance. Accepting the child, along with the syndrome, made the mother feel accepted as well and not alone.

7.3.2. Help and sharing

Quite a few parents seem to gain a lot by helping other parents or by sharing their experience, whether telling theirs to others or listening to the experience of others. Maria, in the following narrative, explains how she decided to help other parents:

M. … since I also talked, through Facebook, with other women who have children with Down syndrome who are older than Christos, and we met them as well. We saw their progress, and so on, we saw the other children. Well, okay, we then were more … let's say, we knew what we would have to face later on (…) This is what I'm trying to do now as well. For example, there is a woman who approached us when she was six months pregnant, umm from Liopetri, from those areas, and I took Christos and we went to talk to her. (…) I took Christos with me so she could see him. She then settled down. Her entire family came, her mum, her husband, their sisters … to see what Down syndrome is!
ED. Yes, yes, yes.
M. Since I wanted to see what it is, I want others to also see and understand what it is.
(…)
ED. You, Maria … how do you feel when you do this? Is it helpful somehow?
M. I do it to help others.
E. Others.
M. Yes. Because I would have liked it, since I never had anyone to help me in that moment, when you don't know anything, just to be able to see and understand that "yes, this baby, this newborn, will make progress. That this baby will become like other babies". Okay, the

baby may lag behind in some aspects, like walking, speaking, but the baby will become able to do everything.

Maria, mother of a 6-year-old child diagnosed with Down syndrome

The mother recounts how she received and then provided help towards other parents. The help concerned plain information about Down syndrome, through direct contact with the child and the parents. Maria had this opportunity of contact when her child was young but she emphasizes how important this help is to parents even prenatally. Through this direct contact, the parent can assess themselves the progression and the severity of the syndrome but also the potential regarding the child's development, offering them reassurance that the child will develop one way or another.

Another interesting point of the mother's words is helping as a circular process: getting help in order to help, at some point, others. Parents, whether needed or actually received help, seem to feel they have to pass on that help to other parents.

Maria in this extract highlights that she is offering this help in order to help others, Antonia in the following excerpt, recognizes that it is also helpful to her to help others:

A. … when I meet other mothers who were like me, I always use hope. That "my baby was like that too, but look at him now".
ED. Yes, yes. This is what you want them to see the most.
A. Yes. To help them. And, okay, in my case, the issue is less severe. (…) Or, for example, Marcos[41] *introduced me to a mother, and he told her, "talk to Antonia, because Philippos was like Petros, but look at him now!" And some other mothers tell me, for example, there was one a couple of days ago who told me "really? He was unable to speak? Him? Wow!". I told her, "yes. Not a word!"*
ED. (faint laughter)
A. And, you know, you feel … wow! (…) Helping them helps me too, yes. Just like there was a woman who helped me as well, whose son was two years older than Philippos, and he was high-functioning. And she kept telling me, "he will speak", "he will stop using diapers". She was telling me what others were also telling me, but I trusted her more because she had experienced it. She was really helpful to me.
ED. Mmm.

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[41] Occupational therapist

A. And I feel that now, when two-three mothers in despair approached me, just like I used to be, I want to help them.
ED. If a person close to you approached you, and told you "you know, my kid exhibits these autistic characteristics". What would you say to them?
A. Well, I have been approached. (…) People who I don't know approach me as well, people who found my phone number. I tell them, "don't worry, it's still early, and there's early intervention. Do your research, hurry up, but don't worry".
ED. You give them instructions.
A. Yes, yes, yes! Practical instructions too, since I'm a practical person. But I happened to receive a lot of phone calls. From friends of friends. I tell them, I will say it "I was crying just like you do. I know how you feel". That's what I tell them. "I know how you feel". (…) And after you tell them, "I was crying just like you do", umm it breaks the ice.
ED. Mmm. Yes, yes, yes. So they feel a familiarity with you.
A. Yes, yes, yes. I also think it's more … if you hear it from a mother, who was in the same position, it's much better than hearing it from a psychologist who … certainly knows, but I believe they may not know as much as a person who has experienced it. (…) And I provide hope. Whoever happens to call me, I speak so positively. Really, really positively. "Don't despair". "I know that you feel despair, but don't despair as much, it eventually won't be as difficult as at the beginning".

Antonia, mother of a 6-year-old child diagnosed with autism

The mother describes how she feels great when she tries to help other parents through her experience with her son with autism. Parents feel trust with other parents of children with disabilities, because the information comes from their experience. They know from their experience that they can understand their despair, which is exactly where parent-to-parent help targets. The sharing of the experience seems to be very powerful for parents, much more essential, according to Antonia, than professional help.

Talking about interacting with other parents of children with developmental disabilities, the mother in the following narrative explains the advantages of the contact with other parents:

E. Of course! Because, you know, in these meetings, we um try over time, umm more frequently in the summer specifically, we try to do things together as parents, with our children. For example, taking them to the park. We all go together. Two-three families, we all take our children to the park. Yes, that's the funny part. That one child is on the swing, hehe, another may be on the slide … and you stand somewhere in-between, hehe, talking *to another parent. (…) Every parent runs after their child, and we talk to one another whenever we get a chance, we're happy to be, hehe, in the park with company. Regardless of the fact that we are not together, because we can't be close to each other. Umm but you feel nice. You feel nice because you don't have to explain anything.*

Elena discusses how parents, in their attempt to socially network with other parents of children with developmental disabilities, they end up feeling the importance of sharing similar experiences with their children. Going to the park all together, whatever the difficulties, is one of the experiences mentioned, underlining though that this experience made them not feeling alone. She then goes on to describe the importance of sharing with other parents but in a different setting:

E. With the therapies that children had to go to, parents had to sit there and wait for them. Right? So eventually, we were sitting and talking while waiting. It was like group therapy [said in English] there, it was really nice.
ED. Haha (laughter). That's great!
E. Because I gained a lot from that. Yes, I gained so much. Because we were taking our children there. Umm we took them to umm do their therapies. Umm … but it was umm it was a good opportunity for the parents to talk about their experiences, where they went, the types of therapies they did, how they helped them, who is the best at providing them. Things of that nature. Those things were a great support (…) Umm it was the contact with other parents, that I saw … Umm let's say, it felt nice there, because you saw that, "I am not the only one, there are others who have people with autism in their families". It was umm something that positively affected the parents' psychology, the positive aspect being that umm I was not alone. That there were others. (…) Yes, it really helped me. I think that was a strong card that I held. Umm little by little umm the … the world kept changing, you were becoming more mature, you kept finding different channels, of professional education (…) you were developing relationships with other people. Communicating with other parents was really helpful. Umm we were having discussions, we learned from one another.

Elena, mother of a 10-year-old child diagnosed with autism

Another argument highlighted by the mother is the importance of parents' contact, whether structured or unstructured and spontaneous, as a safe place to exchange information and feel unconditionally accepted, describing this social experience as "group therapy". The main benefit of parents' interaction is the boost of parents' emotional well-being, thus not feeling alone in their parenting experience of raising children with developmental disabilities.

7.3.3. Self-adaptation and transformation

Another way of coping with the parental challenges and the loss of self is the parents' gradual adaptation, which seems to result in a personal transformation. The mothers, in the following group discussion, debate about how they manage to combine the complex demands of their parenting role:

ED. Umm … And I really wonder how you manage to combine so many things and be so creative and … How you manage to … umm …to do so many things, that, let's say … are not that usual.
An. Law of evolution.
ED. What do you mean?
An. The law of evolution. I mean, umm … it was my project at … when I was studying to get my degree. Umm … why does the giraffe have a long neck? Because other animals ate the leaves that were located lower, so its neck had to become taller to reach the leaves that were located higher in order to survive.
ED. Okay.
An. So we need to do this for our survival. It's … it's something that … in reality, with training, with practice …
ED. You learn of ways to survive.
An. You learn! You learn! We may be lacking somewhere that other parents are … more … but … we find what works best for our children.
(…)
Mn. You don't have a life vest, and you must learn how to swim.
An. Yes! To swim. Yes.
M. You transform! (chuckle)
An. Yes, exactly.
E. You move mountains.
At. You move mountains.
M. But as the child neurologist, Stavrou, said … You do everything and you think that this is normal. Let's say … not normal … I mean, this is your routine and your daily life.
An. It becomes a routine, that's right.

M. Yes! And that … like this … you go on like this. Yes.
Mn. And you don't consider it … You don't realize that sometimes you make extra effort.
M. You don't realize that you make … yes, yes. Everything is done with a flow.
Anastasia, Marina, Maria, Evangelia, Athina (group discussion)

Mothers in this group discussion, examine how they manage to handle the multiple demands of their parenting role along with the losses they have experienced on themselves. The mothers report developing an adaptive capacity – through learning, testing and practice – that allows them to meet the needs of this multifaceted parental identity. As they describe themselves, by using widely available resources, they create the conditions to cope. Further, this transformation is represented as part of a process, as a flow, which gradually becomes automatic to parents.

Other parents also confirm that they experience a kind of transformation. The mother in the following narrative, though, attributes her transformation to different factors:

ED. …. How does this, how does it affect you, these actions that the pediatric neurologist takes? Oh sorry, the developmental pediatrician.
D. I really feel that I, um … went through some kind of, um … (signs) (short pause) um … how to say it, um … that something evolved (short pause) … say it transformation? How to say it, let's say. Totally um ... I mean dramatic changes are happening in my life.
ED. Okay. Hmm, mmm.
D. It is … it is, it is very, umm… powerful to find hope … from someone, and help.
ED. Hmm.
D. And, and to tell you that I am here for, for you.
Demetra, mother of a 6-year-old child diagnosed with Alpha syndrome[42]

The mother, while discussing the broader emotional support she receives from her daughter's doctor on matters not closely related to his specialty, describes experiencing a kind of transformation. Further, she associates this development with the element of hope that this particular professional inspires in her. The mother presents this transformation with a dose of amazement, suggesting the extent she attributes to this change.

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[42] Alpha syndrome is a pseudonym of a rare syndrome.

7.3.4. Summary

The parents are using several ways in order to cope with their parental challenges and the experienced losses of their selves when raising their children with developmental disabilities. Social acceptance, help towards other parents and mutual sharing was the most prevalent ways of coping among the parents of this study. Feeling socially accepted, whatever the condition of the child, seems to helps parents negotiate their situation and communicate it to others within their social context. Help towards other parents also seems to be critical for parents, adopting a circular process of receiving and giving help, mainly through their experiences. Sharing their experience of parenting a child with developmental disability and feeling part of a group of parents who share similar experiences is also significant to parents, generating valuable emotional support for them on the basis of not feeling alone. The parents also report experiencing a kind of transformation, while parenting their children with developmental disabilities, as a result of the need to adapt themselves to the new conditions of their lives.

7.4. Bringing it all together

This chapter examines the self-issues of parents of children with developmental disabilities. The parental role reflects different aspects of parenting when raising children with disabilities, mainly regarding the emotional interaction between child and parent and the fulfilment received by the parental role. A core aspect of parents' role is their multiple care role, when parenting children with developmental disabilities.

Throughout this parenting course, parents describe losing themselves, regarding their own self, their social life and their working role. These losses seem to be somehow connected. For example, loss of work may also be related to loss of social connection for the parents (Kuhlthau et al, 2010).

The parents' ways to cope with these challenges also consist a significant focus of this study. Parents describe finding relief from the social acceptance of their children's disability, from help towards other parents but also from sharing their experience. Lastly, parents report experiencing a kind of transformation, while adapting their selves to the new circumstances following their children's diagnosis.

This study suggests that the experience of parenting a child with developmental disabilities has a transformative effect on parents (7.4.1). Additionally, the parents build a new social self of solidarity through sharing their experience with other parents (7.4.2.). Both arguments, which I discuss in the following sections, confirm the existing literature.

7.4.1. The transformative effect of parenting a child with disabilities

The interviewed parents described their *parental role* as particularly demanding and complex. Their parental experience presumes one or several additional degrees of difficulty, at various levels, affecting directly the *parent-child relationship*. Particularly, the emotional bond between the two is greatly challenged, as the child's difficulties – communication, expression, interaction or else – seem to establish a distance between the parent and the child. The exchange of feelings often appears to be one-sided, with the child not "returning" their feelings, triggering the parent to wonder about the meaning of their own feelings towards the child as well.

The complexity of the parenting role has also been captured in the literature. Woodgate et al (2015) have described parenting when raising children with disabilities as intensive labour, highlighting the need of readiness into providing care at any time. The outcome of this intense care is that parents are being left with minimal or no time for addressing any personal needs, namely social life, vacation, and couple's time. Patrick-Ott (2011) suggests that the chronic sorrow experienced by parents when parenting a child with disability has a severe impact on the parent-child relationship, leading to insecure attachment, lack of closeness, and resentment.

Part of the parental role is *the caring role*, which is very extensive when raising a child with developmental disabilities. The parent becomes educator, therapist, nurse, coach, being always alert and busy. This increased burden of care is made harder by the absence of a break or alternative for the parent where he could feel that he is receiving some support in caring for his child. The multiple caring role is almost exclusively attributed to mothers, with the fathers not being particularly involved and, in some cases, undertaking only a complementary role.

The literature confirms this main aspect of the parental role as care providing. According to McLaughlin et al (2008), care becomes a central condition in parents' life, developing a full-time caring identity. The multiple roles undertaken by parents as well as the intense caring work of parents of children with complex care needs is also emphasized in previous research (Woodgate et al, 2015). Sellmaier et al (2016) suggest the term exceptional caregiving, indicating numerous activities that only the parents of children with disabilities are involved, such as therapies or advocacy of their children with social, medical or educational services. Tong (2002) refers to parents, mainly mothers, as 'dependency workers', highlighting the necessity of this role. Mothers become the predominant carers in the case of children with disabilities (Finch & Mason, 1993), undertaking though the burden placed on them as carers (Sheldon, 1999). Other studies also confirm that the caring role entails a gender bias within the family, as caring of children with disabilities concerns mostly mothers and is integrated into women's role (Skeggs & Creese 1998).

Through this demanding parenting experience, *parents report losing themselves*, their social life and their professional direction. During all these challenges, the child takes the dominant role, becoming the sole point of reference, with the parent putting herself or himself aside. Some parents particularly emphasize on these losses, describing their experience as flattening, as point zero following the child's diagnosis. Indicatively, an interviewed mother describes how she feels that she lost nine years of her life, where the only purpose of her life was to medically follow up and take care of her daughter, with no personal life or goals on herself.

The existing literature has examined the issue of self-loss in parents of children with disabilities. Specifically, due to the increased parenting and caring demands, parents end up to increased isolation, resulting in a decrease of their social life (Holland & Pell, 2018). According to Beresford et al (2007), since the parental role dominates the parents' lives, other aspects of their identity apart from parenthood are minimized, leaving no time or strength to pursue their personal interests or relationships with significant others (Holland & Pell, 2018). Olsson & Hwang (2003) suggest that the social limitation experienced by parents and their subsequent failure to pursue personal goals may generate additional stress. The parents' sense of self identity is severely impacted and obstructed, which the parents themselves attribute to the negative effect of the child's disability on their lives (Holland & Pell, 2018).

The loss of self is also confirmed by the parents' experience on raising their children with developmental disabilities, which was discussed in chapter 6. The extreme dependence of the child on them and the fact that no one might replace them in caring for their child, make parents feel that they are not living for their own selves but for and through their children. Physical and psychological exhaustion but also the total commitment to the child's needs give parents the sense that they have no goals, no life of their own and no desires to fulfill.

Additionally, many parents mention limited or no personal time, due to how time-consuming is parenting a child with disabilities. Some parents express the belief that “their life is over”, meaning life as they knew it until then, since their life has strongly changed.

A significant part of parents’ adult self is their *employment,* which is frequently mentioned in their narratives. It is interesting how many mothers are stay-at-home parents. Indicatively, out of the 26 participants, seven mothers as well as the wife of another participant did not work and two participants had their jobs affected, all with direct or indirect association with their children’s care requirements. Mothers are the ones who choose or end up not working and devote themselves to caring for the child with disability. On the other hand, fathers claim that they either differentiate their working conditions or choose to work more in order to be able to ensure the increased needs of their children, many of which related to the diagnosis of the child.

Parents’ employment seems to be highly related to the loss of self, since it is represented as a critical factor to whether parents have a life themselves beyond parenting their children. Alongside with the loss of the working adult self, parents – almost exclusively mothers – take on a different unpaid job, that of the multifaceted child’s permanent care, including educational, therapeutic, administrative and other duties. Consequently, when parents change or quit their job because of the child, they feel that their personal adult life – their course of life and their choices – is at risk. Mothers who have taken on this role – not working, fully devoted to the child – seem to experience more intense negative emotions, as work seems to be represented as a break or as taking a breath.

Existing studies examine how parenting of children with disabilities is related to employment. According to Brown & Clark (2017), the balance between family and work is significantly more difficult for parents raising children with disabilities. Pierce et al (2019) highlight the parents’ lower employment rates, especially for mothers, because of the lack of appropriate and affordable childcare for children with disabilities. Wondemu et al (2022) discuss the relationship between raising children with disabilities and the reduced parents’ participation in the labour market, their working hours and their earnings, with the negative impact being more definite for mothers than for fathers; they also found a stronger influence on the parents’ employment when parenting a child with severe disability. Parents of children with disabilities when employed experience increased stress and difficulty in fulfilling their work responsibilities (Wondemu et al, 2022).

However, parenting a child with disabilities entails the *parents’ personal development*, which parents describe as a *transformation*. The challenges of the parental role, the parents' losses, combined with the highly demanding parenting experience seem to trigger the parents' gradual development, achieving a form of personal growth through the adversities of their parenting course. Using terms like transformation and metamorphosis, the parents liken their condition to the law of evolution: precisely due to the degree of difficulty of the parenting experience, they manage to evolve, to adapt and finally to survive. Parents – mainly mothers – describe as the cause of this "transformation" the need to survive, the need to adapt to the new conditions of their child's disability. This is about a process of learning and processing mainly practical stimuli, where the parents manage to identify the ways in which they can help their children and themselves. Other parents attribute their personal growth to the support they receive from others, inspiring them with hope and perspective for change.

The idea of parents' personal development and transformation when parenting a child with disability is not new in literature. Scorgie et al (2004, p. 85) describe the parents' experiences as "personally transformative", although they encounter significant and continuing challenges when parenting children with disabilities (Green, 2002). The parents' adjustment to their new life circumstances is achieved through the learning to adapt (Leung & Li-Tsang, 2003), as suggested by this study as well. According to Kausar et al (2003), parents of children with disabilities experience personal growth, which they attribute directly to their children with disabilities. One of the main arguments on the basis of this transformation is that parents finally find ways to cope: despite the increased demands of raising a child with disabilities, parents are found able to manage life effectively (Scorgie et al, 2004). Other than that, parents also report positive outcomes when parenting children with disabilities (confirmed by the findings of chapter 6), such as stronger family bond, increased sensitivity to socially excluded people and development of the ability to identify what is important in life (Scorgie et al, 2004). The positive outcomes of parenting a child with disability (Beresford, 1994) includes improving adaptive characteristics (Elllis & Hirsch, 2000; McLaughlin et al, 2008). Scorgie et al (1996) discuss about parents' transformation into three themes: personal, namely changes in their self-identity, relational, namely changes in the relationship with others, and prespectival transformation, namely changes in their perception about what is important in life.

Other studies explore the concept of post-traumatic growth or the growth through adversity, reviewing the responses to several traumatic stressful events. Joseph & Linley (2006) suggest that a highly demanding, stressful and traumatic incident may be the trigger for the person's personal growth or, possibly, the positive change. Similarly, Linley (2004) proposes that personal growth is an element found in suffering. People who experience a severely difficult life event, usually report that they have been blessed or that they have benefited from this experience, which is confirmed by the findings of the present study.

Therefore, this proves that stress can also have a positive impact in consequence and that the main and “more important role of coping may be transformation” (Aldwin, 1994, p. 270).

Consequently, this study confirms the existing literature regarding the parents’ self adaptation and transformation. Since the parental role is not fully or it is differently fulfilled and care is complicate, the parents seek ways to cope through this stressful experience, they change, adapt and are finally transformed. At the same time, the self-losses experienced by the parent urge them eventually to develop capabilities – as an adaptation mechanism to all these challenges – because due to these losses, parents need new ways to function adequately. Therefore, parents respond to these needs – that is, the blend of the demands of their parental role and their personal-losses – by changing and achieving personal development. The outcome of the experienced tremendous change of the child’s disability in relation to the fact that parents are coping is that parents are changing in order to cope.

It is interesting that the parents describe this transformation as a process: through knowledge and effort, they find ways and resources to adapt to new conditions. This process gradually becomes automatic and part of their everyday life. However, some differences between mothers and fathers seem to be reflected in their course of development. This “transformation” appears to become more automatic for mothers, becoming part of their lives, while for fathers there seems to be an element of drift of responsibility, without actually involving themselves. This is mainly related to the mothers’ role as carers, which is dominant. According to McLaughlin et al (2008), there is a gendered division of care when it comes to parenting children with disabilities, as mothers are easily represented as carers for themselves and for the others, while fathers’ roles as carers are not easily recognized by others. Consequently, the transformative effect of parenting a child with disabilities is probably stronger and definitely more usual in mothers.

What I suggest is that parents experience particular challenges in their parenting role. Additionally, losses – of self, of social life and of their work role – create a need for change in order to cope. Consequently, parents change, evolve and eventually are transformed. In this way parents manage to cope, to connect with their personal and social context in a way that they feel safe. In addition, parents manage to reshape their parental role, with the new facts of their child's disability. This transformation helps parents find or invent another "self". Besides, the parents’ experienced losses, for example of their social life, help parents to find another social life, through solidarity and help from other parents (further discussed in 7.4.2). Finally, this transformation contributes to the fulfillment of their parental role: the parent gains hope and motivation to further develop his parental role, either in terms of the relationship with the child, or in terms of his caring role.

The usefulness of this proposal lays on the fact that there can be change and growth in parents without necessarily overcoming the stress, the burden, or the struggle experienced by parents. Along with what happens to them, the parents learn to survive, with stress and transformation co-existing. The parent's experience of stress or negative emotions, does not mean not evolving but, on the contrary, denotes parents' personal development and transformation.

Another interesting point here is that parents take responsibility for this change. There is an important element of agency, where parents experience this process of change in purely individual terms. There is no available support, any form of state or other support, where parents can derive resources, information or emotional support in order to directly or indirectly help themselves throughout this change. It is interesting that even the social elements, from which the parents derive support (i.e. sharing with others), are found by themselves in their environment, with their individual initiatives and are not supported by any formal institutional way. This element is indicative of the support gap that exists in the local social context. Thus, the parents themselves, with individual resources and initiatives, taking on their full agency, they gradually build the ground and achieve their personal transformation.

7.4.2. Building a new social self: sharing and solidarity

This chapter focuses on the parents' challenges when raising a child with developmental disability, resulting in not achieving the fulfillment of the parental role. Specifically, parents report the lack of satisfaction in their parental role, struggling to contact or bond with their child. This impacts immensely on the child-parent relationship, since the parental role cannot be experienced without restrictions. Additionally, the complicated care needs generate a strict context of experiencing the parental role. The complexity of care concerns a caring role more intense, more time consuming and more long-lasting compared to the typical parental care.

Another difficulty of the parental role when raising children with disabilities is the parents' losses of self. Parents discuss losing themselves, their social life but also their working status. These losses seem to be interconnected, since the loss of the working role might influence one's social life, or losing oneself might impact the loss of social life. This idea is confirmed by literature, as loss of work may also be related to loss of social connection for the parents (Kuhlthau et al, 2010). Some parents report losing part of their selves after their child’s diagnosis, which might include losing the contact with others, the contact with oneself or losing – on not managing to build – the contact with their children. The satisfaction from the parental role involves emotional sharing with the child, which also seems problematic or even not possible. Consequently, the parent might turn to significant others to satisfy their need for emotional sharing.

However, by *building a new social self*, based on *sharing and solidarity*, parents respond to the self-challenges arising from the child's disability. Firstly, sharing makes parents feel connected. The parents themselves report that feeling integrated and accepted is crucial for them. Parents, through helping and sharing, feel they are in control, they take significant decisions about their social presence and abandon the passive attitude of the suffering parent. Additionally, parents seem to feel important – but at the same time they are really significant to other parents – when other parents approach them to learn from their experience. Therefore, parents attempt to build a new social self, based on solidarity and sharing, precisely to balance their losses of self.

Through this new social self, parents seem to find meaning and perspective in their lives by investing in solidarity and sharing their experiences. For example, by strictly following the professional’s prognosis, parents seem to limit themselves into the future child’s difficulties or the developmental challenges that need to be handled. By adopting, though, the "future" of solidarity, parents seem to gain meaning in their lives. In this way, parents appear to obtain a purposeful reason of being, by building a functional role that gives them meaning. Additionally, while having lost contact with themselves, with their child and with the social environment, parents regain contact with "the other", by sharing their experiences or by building a solidarity self. Thus, they re-enter society, “recovering” a lost part of themselves, which includes caring for others and socializing. The in-group interaction allows parents to feel useful, giving them a sense of belonging.

This is made obvious by the parents’ articulated need to connect with other parents raising children with developmental disabilities, which they pursue. Contact with other parents is described as comforting, both for the parents initiating the contact and for the parents receiving it. Some parents make special reference to how their participation in the discussion group affected them, where the sharing of experience within the group led them to important realizations and personal development, such as feeling proud of having a child with autism. The importance of contact with other parents is also quite supported by the findings of chapter 6, where parents describe their relief when they realize that they are not the only ones experiencing similar situations or that they don't need to explain anything during their interaction with other parents. This contact responds to the parents' feelings of loneliness while providing them with enough readiness for what they will face in the future.

Furthermore, by building this new social self, parents look at the future, investing in some sense in solidarity. Instead of emphasizing on their losses, which would detain them in the past, parents look towards the future of solidarity, redefining the meaning of "together", combating the loneliness of their parenting experience and finally empowering themselves. Parents become each other's "therapists" and through that they find ways to keep on. They find meaning and hope through this interaction.

Solidarity comes as the result of parents' helping towards other parents and sharing, which seems to be developed as an escalating process. Help towards others seems to progress to mutual help, support and solidarity, establishing an interaction for sharing.

The need of parents to share their experiences and reach out with other parents has also been discussed in the literature. McLaughlin et al (2008) introduce the concept of the allied parent, who seek to develop active positions or actions of alliance with other parents of children with disabilities. Parents help other parents and share their experience, hoping that this way they are contributing to some change for themselves and for others, dealing as well with social isolation (Kagan, 1998). Parents' alliances and mutuality of relationships with other parents in similar circumstances influences fundamentally parents' identity. Parents feel included and accepted, because they feel they share precisely this acceptance of difference with other parents (McLaughlin et al, 2008).

Regarding parent-to-parent support, Solomon et al (2001) suggest that parents receiving peer support feel increased self-esteem, confidence and less guilt, but also experience changes in their relationships with the others, gaining a sense of control and agency. Other studies propose networking, as an essential way of social support between parents, since it allows parents to help other parents, by sharing their own experience and other valuable information, which in turn has a vital stress relief function for parents (McLaughlin et al, 2008). The networking support might nowadays be personal or online (Fleischmann, 2004). According to Bray et al (2017), mutual support has a positive impact on parents' levels of distress and on their ability to cope with parenting a child with disability, since parents move from being lost, to being a guide for other parents. The sense of social isolation and loneliness that parents often report seems to be resolved with parent-to-parent peer support, which help parents develop a sense of connectedness with other parents (Bray et al, 2017). According to Solomon et al (2001), parents who are members of parents' groups become active participants instead of just recipients, given that the birth of a child with disability often puts parents into the position of recipient.

Consequently, this study *confirms the idea of sharing and solidarity* among parents of children with developmental disabilities. *Building a new social and solidary self*, functions as a balancing act which seems to restore parents' feeling of being in control of their lives. Having lost their selves, their working status and their social life, parents develop a new social self of mutual sharing and support. This new self offers parents the sense of belonging to a group – the group of families of children with disabilities – the feeling of being understood and accepted and the sense of having friendships and social networks where they could share emotions and feel accepted. The importance of sharing between parents of children with developmental disabilities is also connected with the "therapeutic" factor of sharing, namely the development of empathy, acceptance, catharsis and universality. This includes the parents' psychological well-being, with direct impact on their confidence, their self-esteem and their guilt feelings. The contact with other parents provides a unique experience of recognition, belonging and feeling valued as a parent, described by parents as better than professional support. Finally, parents are benefited by sharing their experience, since they limit their sense of loneliness and, at the same time, they satisfy the need of being important to someone else while distance themselves from the tragic representation of a parent of a child with disability.

To conclude, all the burden of the parental role – the strict limitation in serving and caring parental responsibilities and the absence of the elements that give satisfaction and alleviate the burden – the difficulty of connecting with the child but also the pervasive loss of the identity that extends beyond the parental role, all these seem to be "answered" by parents with social connection. Acceptance from other parents, sharing and solidarity are important factors for parents to shape the conditions in order to build their new social and empowered self.

Chapter 8: Conclusion

The aim of this chapter is to reflect on the findings of this study and to consider its input in existing literature and practices. Initially, I summarize the findings of this study by considering their contribution. Then, I focus on the main concepts discussed in this study – namely ruptures, meaning-making and coping – and their implications for literature. Next, I present the practical implications, the limitations as well as the future directions arising from this research. I close this chapter with some final thoughts on the entire study.

8.1. Summary

8.1.1. The milestones of the parenting experience

This research began by exploring the *main milestones of the parenting experience* of parents raising children with developmental disabilities. The *experience of the announcement* of the diagnosis was the first milestone discussed, which has mainly been recorded by parents as a negative memory. A second point emphasized by the parents is the inappropriate approach of the professionals, who in most cases reflect negative representations of the diagnosis, at other times they adopt a power position towards the parents while most of the time they choose an abrupt and without empathy way of announcing the diagnosis. However, some parents seem to appreciate this direct way of announcement, which motivated them to take immediate action for the child. The announcement of the diagnosis was also described by the parents as a disorganized and unstructured process, a chaotic situation that caused anxiety for the parents.

Parents described different patterns regarding the *initial reception of the diagnosis*. The initial shock and the feeling of generalized sadness, similar to that of the loss of the child, emerged very powerfully in the narratives of the parents. Some parents presented this first reception of the diagnosis as a traumatic event. Additionally, several parents discussed the lack of knowledge they found they had regarding the diagnosis when this was first announced to them. Finally, some parents emphasized that they needed some time to understand the diagnosis.

The parents' *long-term reception* of the diagnosis was also discussed in three patterns. Several parents stated that they accept their children's diagnosis. Acceptance, however, is experienced differently by parents: some accept the diagnosis as a no-choice process, others describe acceptance as grounding to the reality of the diagnosis and others discuss about acceptance as a process. Some parents consider that they have not accepted the child's diagnosis while others prefer to keep some distance from the diagnosis label.

The following section dealt with the discussion of *what helps parental acceptance*. Many parents find it helpful that their child's diagnosis is a common problem affecting many other parents apart from them. Other parents debate about the realization of their child's difficulties through time while others find helpful the comparison with the so-called worst-case scenario. Some parents involve in a kind of negotiation regarding the label of the diagnosis, emphasizing or ignoring certain points of the diagnosis. Finally, parents highlighted the appropriate state or professional support, which if available would be very relieving in terms of accepting the diagnosis.

The chapter continued with the *parents' interpretation of the diagnosis*. Several parents adopt the interpretation of the randomness of the diagnosis while others consider the diagnosis clearly related to medical reasons. Some parents present the diagnosis as their responsibility, either indirectly or directly, due to heredity, family planning (related to reproductive age) or factors related to pregnancy or childbirth. Finally, some parents interpret their child's diagnosis as related to God or some other superior power.

Lastly, the *social dimensions of the diagnosis* were discussed, as an important milestone of the parents experience of the diagnosis. Several patterns emerged when considering the social context and the dynamics developed with the different others, with the first one being misunderstanding and conflict between the parents and difficulty or lack of understanding within the extended family. Parents also report loneliness and distance with their partner or with the other child of the family. However, the opposite pattern was also obvious, with some parents describing support and deep connection with their partner and within the family setting. In terms of the broader social context, parents discuss feeling stigmatised in several ways because of their children's diagnosis.

Overall, I suggest that instead of approaching the parents' reactions to the diagnosis in terms of acceptance and resolution, as literature suggests, *parents in this study experience an ongoing process of negotiating their children's diagnosis* following the – mainly problematic – announcement and during their experience of parenting their children with developmental disabilities. Understanding the parental experience serves a dual purpose. First, by better understanding the experience of parents as an ongoing process of negotiation, emphasis is placed on what the parent feels and how they go through their parenting experience, placing the parent at the center of their experience, allowing their true needs to emerge and to be understood. Further, by placing the parent at the center of their experience, the power role often adopted by professionals is been challenged, motivating the development of a cooperative or alliance relationship between parents and professionals. Second, by shedding light on the process of the parents' experience, there is a direct benefit for professionals, the extended family or the family's immediate environment in their interaction with parents, since they get to better understand the parents' experience. This proposal is, particularly, important for professionals in order to move away from placing the emphasis only on their professional understanding and from the dichotomy of the parents' acceptance or non-acceptance of the diagnosis. By extension, if others understand, parents are also indirectly helped to have a better experience of parenting their children, by the others' better understanding on their needs. Essentially, the contribution of this approach is mainly found in the importance of having a “map” that allows others – professionals, extended family, immediate environment – to better understand the experience of parents and their needs.

Additionally, I propose that the parents negotiate the representation of the child's diagnosis as a problem, which they deconstruct by transitioning from the use of medical discourse around the diagnosis to a social discourse. This approach showcases the pivotal role of the experience of the diagnosis for the parents. The diagnosis has very significant implications in the processing and progression of their experience both for themselves individually and on their interaction with others, regarding for example their feelings, their isolation or not, their reaction against stigmatising behaviours. These implications emerge important practical suggestions, concerning parents' support, further discussed in chapter 8.3.

8.1.2. The parents' personal experience

This chapter aimed to outline the parents' experience of raising their children with developmental disabilities. Initially, I discussed the *parents' meaning on their parenting experience*, which is depicted in five themes. Some parents represent their experience of parenting as a hefty burden and others as a constant struggle. Other parents experience their parenting course as a blessing, describing how fortunate they are of raising “such a child”. Another interesting representation on their parenting experience is describing it as a ‘no-different' parenting experience, as an experience of parenting among others. Lastly, parents emphasize their lost expectations regarding their children and their parenting experience.

Regarding the *parents' feelings on their parenting experience*, several clusters of feelings were illustrated in parents' narratives. Parents report feeling angry and questioning 'why' regarding their children's diagnosis. Some parents describe increased stress and feeling tired throughout their parenting experience. Another cluster of feelings emerged from parents' discourse is pain-related feelings, such as trauma, loneliness, failure and feelings of loss. Fear is also quite prevalent within the parents' experience, often accompanied with uncertainty and insecurity. However, parents represent their parenting experience with positive feelings as well, such as satisfaction, pride towards the child and hopefulness regarding the future. Lastly, some parents describe how their feelings are related or motivated them for action concerning the child.

This chapter closed with the discussion of the resources used by parents throughout their parenting experience. Parents are found to use everyday practices, such as going for walking, and rituals, such as statement writing, as resources in order to cope with the demands of their everyday experience of parenting their children. Religious faith is another important resource used by parents, through personal prayer or pilgrimage. Additionally, parents report trust in human power as another resource they use, which has to do with the belief in their child's potential, the parents' belief in their own power but also in other people's power, such as professionals or other parents. Lastly, parents describe how they practice researching, information seeking and involvement in parents' associations as significant learning resources throughout their parenting experience.

Based on the findings of this chapter, I propose a spiral nature of the parents' experience, according to which the parents' experience involves several positive and negative aspects – such as blessing and burden, loss and gain, which are connected with/in a circular way, creating a conceptual continuum, which I describe as a spiral. The movement between these oppositional aspects is continuous, indicating the process that parents experience, where at times they focus on the negatives and at other times on the positives. The contribution of this approach is triple. Firstly, the contribution lies in 'reading' the parents' experience over time rather than describing aspects of their experience in an isolated time frame. In other words, I place the experience of the parents in a temporal horizon. Parents continue to experience their parenting long after their child's diagnosis and I highlight their experience as a process. Secondly, this approach is important because it represents the parents' experience not as positive or negative in a single dimension, but as a multi-dimensional complicated experience of parenting. Lastly, the contribution of this approach focuses on the parents' experience as a critical life changing event, which evokes very contrasting and extreme feelings and meanings for the person experiencing it.

Another conclusion of this chapter is the parents' contact with other parents as a 'normalization' coping mechanism. The 'normalization' coping mechanisms refer to the processes by which parents attempt to establish a sense of normalcy in their lives, despite the challenges of parenting a child with disabilities. By contacting other parents in similar situations, parents develop a sense of belonging into a community, finding relief and feel empowered. Initially, the contribution of this approach is to identify how parental contact with other parents seems to essentially "deconstruct" the concept of normal, and to place parents within the wider society, giving them an active role, which has several implications in terms of its practical applications (see chapter 8.3). Another contribution of this approach concerns the parents' attempt to position their 'non-normal' children with disabilities alongside/as equal to 'normal'.

This chapter closes with an emphasis on the function of hope. Parents use symbolic resources, such as blogs, to mediate the rupture of their experience, thus the burden, the struggle, the uncertainty and the fear, generating hope in the long run. The contribution of this approach is found on the use of symbolic resources, which serve as tools in order to help parents cope, to redefine their roles and to find meaning in their experiences. Parents present dynamics in their search for meaning, they create ways to maintain hope, which is indicative of a parental agency.

8.1.3. Parents' self-related issues

This chapter discussed the parents' self-related issues throughout their journey of parenting children with developmental disabilities. Regarding *the parental role*, the parents illustrate how the child-parent relationship and the fulfillment of the parental role are greatly impacted by the child's disability. Further, the parents emphasize the multiple caring role they undertake due to the child's increased needs for care, such as basic need care, education, therapies and more.

Parents also seem to prominently discuss a *loss of self*. Parenting a child with developmental disabilities brings some significant losses for the parents, such as negligence of the self and loss of their social and work life.

This chapter closed with the discussion of the *parents' coping regarding their self losses and their parental challenges*. Parents describe the significance of social acceptance, from the close and the wider social environment. Another element that helps parents in their parenting role is helping and sharing with other parents. Finally, parents' coping involves developing a new aspect of themselves through sharing their experience and building solidarity with other parents of children with developmental disabilities.

The conclusion of this chapter is that parents change, achieve personal development and transformation, as a result of their particular challenges in their parenting role and their personal losses throughout their parenting experience. This finding confirms existing literature. The contribution of this approach is found on the fact that parents develop an agency towards change, meaning that they self-regulate any potential change, without relying on any kind of external help (i.e. professional support). This is of course partly due to the fact that this external help is largely missing, a point discussed further down. Another contribution of this approach is related to the fact that parents can change and experience growth without necessarily overcoming the stress, the burden, or the struggle they experience. Therefore, parents experience negative emotions or stress, which in a way contributes in parents' personal development and transformation.

8.2. Ruptures, meaning-making and coping

This chapter discusses the main findings of this study using the concept of ruptures (Zittoun, 2006) and of meaning-making efforts (Valsiner, 2007) that parents engage with along with the coping processes they use to respond to the challenges faced (Kadianaki, 2014). I attempt to summarize these findings and emphasize the new ideas they add to the existing literature.

8.2.1. Parents' ruptures

Regarding the idea of rupture, as explained in chapter 3.2.2, I propose here a conceptualization that introduces some new ideas in the theorization of the rupture. I suggest that parents raising children with developmental disabilities experience a lifelong rupture on several levels, from the announcement of the diagnosis to the present.

As explained in chapter 3.2.2., a rupture is a disruption in the regular flow of everyday life, which is experienced as a discontinuity in the standard course of ordinary life. A rupture is followed by a period of transition, during which the person is found to experience imbalance and uncertainty that needs to be resolved and dealt with (Zittoun et al, 2003). Zittoun emphasizes the concept of rupture in order to explore issues of psychological development and change. The concept of rupture seems to demonstrate some interesting aspects and dimensions in this study.

Parents are found to experience various levels of ruptures during their journey of raising their children with developmental disabilities. First comes the rupture of the diagnosis, where the parent is confronted with a precipitous, unexpected and shocking announcement, crushing any previous condition of certainty. The diagnosis of the developmental disorder is often something completely unknown to the parents, causing stress and anxiety. Additionally, as the parents themselves describe, the diagnosis is not introduced to them in terms of empathy but is announced to them abruptly and shamefully. Already from the announcement of the diagnosis parents receive pity and discredit from the professionals, placing them in a vulnerable position. The announcement of the diagnosis is experienced by the parent as a defining traumatic life event, which accounts as a rupture related to a change within the immediate environment of the parent (Zittoun, 2004; 2006), causing uncertainty and instability.

However, the rupture comes back on different terms throughout the parents' experience. During the long-term negotiation of the diagnosis and of the experience of disability, parents are found to go through great ambivalence. While processing their relation with the diagnosis, parents experience conflicting and mixed feelings and thoughts: they wonder whether to accept the diagnosis or to keep some distance from the diagnosis label, they recognize the signs of the diagnosis but rejecting the terminology of the diagnosis, they admit having no choice but acceptance while they concurrently feel that acceptance is competitive to the effort of progress. Therefore, parents are found to continuously vacillate between conflicting meanings and experience a generalised form of ambivalence. Abbey and Valsiner (2005) define ambivalence as the tension produced by a system of a nucleus directing at two at least non-equal trajectories. The most typical, according to them, form of ambivalence emerges when two equally strong forces shove the person in opposite directions, resulting in the maximum degree of ambivalence. This is the case for the parents raising children with developmental disabilities, experiencing a profound degree of ambivalence between the present and the future, reinforcing the trauma generated by the diagnosis itself, undoubtedly signaling a different kind of rupture.

Last but not least, the parents are found to experience the rupture of parenting, the rupture of a life experience perpetually traumatic. This level of rupture concerns an internal struggle that the parents seem to be going through regarding the experience of parenthood, which is perceived as the ‘end of their life’. Parents seem to place the diagnosis in the background and describe a parenting experience that is constantly overwhelming and riveting. Loss is the main foundation of this rupture, as a traumatic experience that they might not recover from: loss of the expected child, loss of self but also loss of the ideal parenting experience. Simão (2003) argues that people who come across a gap between expectances and experiences encounter an intense rupture of the normal, typical flow of life. The burden of parenting when raising a child with disability also consists a pivotal element of this parenting rupture. Parenthood is experienced as an internal struggle between the loss of the meaning of life and the undeniable need of the continuity of life. It is interesting to highlight that this rupture touches more existential aspects of their parenting experience, which is a lifelong experience, making the rupture as well lifelong.

Part of why parenting is experienced as a multiple rupture is the specific socio-cultural context and the ideas around parenting, children and disability that exist in this context. In the broader social context, parents live and raise their children in a social context with strong negative social representations of disability. These social representations permeate every type of communication and interaction of parents. Already from the announcement of the diagnosis, parents strongly receive stigmatising treatment and rejection, even from professionals. They avoid communicating the diagnosis to the family, to protect older members, confirming that they themselves internalize the stigmatising social representations. In the social context, charity prevails (Symeonidou, 2009), limited accessibility to all areas of life, insecurity and isolation of people with disabilities and their families (Symeonidou, 2015). Appeal to emotion is the common practice to talk about people with disabilities (Symeonidou & Phtiaka, 2014) while inclusion and integration are still in their primary stages (Symeonidou, 2015). The parent raises a child with a developmental disability, who represents the other, the different member of society. Additionally, the state framework for parental support is completely absent, parents feel that they have absolutely no support, that they are completely isolated within their family milieu and that any networking effort is done on their own initiative (Phtiaka, 2006).

In the personal context, there is also significant indication suggesting the parent's experience as rupture. There is an intense loss of the self, a loss of the self that the parent used to be, involving the loss of the social self and/or the loss of the identity as an employee. The loss of self constitutes a pivotal discontinuity, experienced as an individual rupture. Parents also experience very strongly the loss of the relationship with their partner, either due to serious conflict following the diagnosis or due to ‘estrangement’ or even due to practical difficulties, such as continuous engagement with the needs of the child. The rupture is also evident through the experience of the child's disability, where the parents experience frequent inadequacy in their parental role, such as nurturing or caring for the child inside or outside the family setting – which they describe as traumatic experience – generating a rupture in the ordinary course of the parenting role.

Consequently, the rupture experienced by parents begins with the child's diagnosis and ends in a lifelong rupture, a rupture that parents experience at different levels and on different terms. Initially, the parents are confronted with the rupture of the diagnosis, an unexpected and defining life event that turns out to be traumatic, causing a rupture in the condition of certainty until then. Parents then vacillate in opposing meanings regarding their negotiation of the diagnosis, experiencing intense ambivalence. Finally, parents encounter the rupture of parenting a child with developmental disability, which they express as the end of their live, experiencing it as an internal struggle and a permanent traumatic experience. Therefore, the parent is constantly confronted with a trauma on different levels and experiences parenting as a lifelong rupture. This is an innovative idea about ruptures, which I suggest as a conclusion of this study: parents raising children with developmental disabilities experience a lifelong rupture on several levels, a pervasive rupture that permeates the entire parental experience and the parents' whole life, from the announcement of the diagnosis to the present.

8.2.2. Parents' meaning-making

This section discusses parents' meaning-making efforts. What I suggest as an interesting finding regarding meaning-making is that parents create dipoles of oppositional meanings throughout their experience of parenting children with developmental disabilities.

In this context, I discuss meaning-making as vital to understanding the parental experience. Meaning-making is, thus, approached as a tool for human actions (Valsiner, 2007) in order to mediate their thoughts, feelings and actions through cultural means/signs (Valsiner, 1998). Accordingly, parents use meaning-making as a tool throughout their experience. Meaning-making appears as a process at various points in the parents' experience raising their children with developmental disabilities. I will discuss three thematic units of meaning, as they emerged through the parents' discourse: blessing, 'normalization' and parents' responsibility.

A meaning-making effort often emerged from the parents' discourse is their experience raising their child with developmental disability as a blessing. Parents often state that they feel blessed, they feel lucky to live this unique life experience, which often turns out to be a gain for them: they have learned the meaning of life, they are not concerned with trivial and insignificant things, they have developed as individuals. However, the meaning of blessing comes to their narratives often as the other side of another meaning, such as the struggle, the burden, the trial that they go through or even the fact that they don't care only about themselves and show self-centeredness. Parents feel fortunate to experience this blessing over trial, struggle, burden, or self-centeredness. This meaning of the blessing works somewhat reflectively, mirroring the great worries, anxieties and distresses of the parents: how will I manage this trial or this struggle? How will I carry this burden, how will I manage to find myself in all this chaotic experience? Parents engage in this meaning-making of blessing which challenges the perspective of the struggle and the burden. This meaning-making effort is clearly comforting and possibly relieving for the parent.

This meaning-making derives its meaning from religious discourse, almost imitating the so-called word of God: trials are here to test you and make you a better person, therefore you are blessed to experience each trial, and you should be grateful for that. Hence, parents are integrating elements of their already used tools, such as religious discourse, by which they create the meaning of blessing. According to Abbey and Valsiner (2005), all meanings are created in the present, integrating elements of past experiences, in relation to a future that can never be entirely determined at the present.

The parent claims that it is a blessing to parent such a child, feeling fortunate to experience it, and thereby reflecting and easing the burden and lessening the trial. In fact, the parents discuss about the blessing of their experience while smiling, expressing their enjoyment for it. This seems to be an element also probably derived from the religious discourse and the general appeal for gratefulness. However, it seems to also have a reverse function: through the excessive positive description, the parent seems to reverse the worries and balance their experience through the meaning produced: 'I may be living a trial, carrying a burden but I'm laughing, I'm happy, and this is because I am experiencing a blessing'.

Overall, I suggest that the parents' meaning-making of blessing is a tool that facilitates parents to balance and conceptually ease the trial, the burden and the difficulty they experience during the experience of raising their child with developmental disabilities.

Another meaning-making process quite obvious in the parents' discourse is 'normalization'. Parents make sense of their experience parenting their children with developmental disabilities as normal, as a different experience of normality. This parenting experience may be unfamiliar to most people but they represent it as normal, either by claiming their place in the 'normal' society, or by expressing a reaction to the others' representation of them as non-normal or by presenting the normal aspects of the life with their child. Additionally, parents emphasize on incidents perceived as worst-case scenarios (i.e. severe physical disability or parenting two children with disabilities), reporting and openly discussing such scenarios, which make them strengthen their meaning as normal. They also highlight the randomness of their children's diagnosis, as a strong validation of the normal discourse. Namely, they attribute the fact that they have to raise a child with disability as a random, non-explicable incident, and as one of the many difficulties of life that one may experience. If I want to put the parents' meaning-making effort in a sentence, it would be 'I am fine', 'my child with disability is normal' or 'we live like common people'. Therefore, parents construct a normal parenting experience.

However, here as well, very contrasting meanings emerge in terms of the 'normalization' of the experience. The parents strongly express their concerns for all things that the child cannot or will not be able to do in the future: to have a job, to live independently, to live 'normally'. Everything that shows that a person is normal may not be accomplished by their children. Additionally, there is a strong reflection of the separation between normal and non-normal, through comparisons of the child with 'normal' children, siblings or others. This comparison is very distinctive in the case of twins, where one of the two is a child with disabilities. Besides, another powerful meaning which appears in parents' discourse it the child's objectification, reflecting a de-humanized conceptualization of the child, aligning with the meaning of non-normal.

In this meaning-making effort, as well, the parent constantly moves between the meaning of the normal and the non-normal, revealing an intense ambivalence. Parents' meaning-making efforts also tend to de-normalize, to underline the difficulties and the non-normality of their child seems to reflect the parent's anxiety, pain and fear for the present but especially for the future. I suggest that parents' meaning-making tendency to normalize their experience, to represent their child and their parenting experience as normal through the meaning-making of the normal experience, seems to reflect the sense of hope or perhaps even the innermost unconscious desire of the parent, denoting what the parent longs for, namely to live like a normal person and to raise a normal child. The child, though, is not 'normal'. Therefore, the parents make meaning in order to balance fear and anxiety and open the access to hope. This meaning-making effort related to normal enables the parent to create meaning in order to allow their conceptual 'contact' with hope, by balancing or diverting distressing ideas or thoughts.

I could suggest that this meaning-making effort derives its meaning from the medical discourse, where the separation between 'normal' and 'non-normal' is strongly used and the comparison with what is considered average and typical is a usual practice. This meaning-making is a somewhat explanatory meaning-making effort, with parents indirectly expressing a deeper need to explain their relationship with normal. The parents turn out to represent the child with disability as a different ‘normal’, as a ‘non-typical normal’ but not an inferior or worthless individual, somehow deconstructing the concept of ‘normal’, by detaching it from the medical discourse. This meaning-making process, however, could be said that it reflects the parents’ need to reassure themselves, regarding their child and the disability, by approaching their child's condition and their experience as normal: the child has got a disability but it is fine, in the sense that it is part of human diversity and existence (Waldschmidt et al, 2017). Consequently, they approach their parenting experience as a normal parenting experience.

Overall, the parents are involved in the ambivalence of their meaning-making effort around normal. The meaning of normal enables the parents to normalize their children’s disability, namely to balance their fear and anxiety generated by the meaning around non-normal and allow the parent to create meaning around the normal, by representing their child and their experience as a different normal.

Another meaning-making effort that was identified in parents’ discourse regarding their experience raising their child with developmental disability is the child’s disability as their own responsibility.

The meaning of responsibility is pervasive in the parents' narratives and emerges in various dimensions. The first dimension is more abstract, where the child is an existential continuation of the parent, meaning that the existence and development of the child is indirectly impacted by the parent. The parents often wonder if and who their children look like. Based on a similar rationale, the parents of children with disabilities wonder whether their children's disabilities are a continuation of their own existence and therefore their own responsibility, due to hereditary or genetic factors. The meaning of responsibility, however, also appears in a practical dimension. Parents feel responsible of their children’s disability because they were late in having a child in terms of family planning, because they were late in being admitted to the hospital the day of the child’s birth, because they were vaccinated, because they experienced stress during pregnancy, or even for the sins the parents committed and are "paid" with the child's disability. It is interesting to note that this practical dimension of the meaning-making of responsibility concerns mostly mothers (Traustadóttir, 1995; Finch & Mason, 1993; McKie et al, 2002). Some parents construct meaning on their responsibility as their personal failure, in the sense that they did not manage to have their child born normal, directly recognizing their failure.

This meaning of responsibility, however, seems to have a restorative meaning. Parents speak openly of responsibility and I suggest that since this has an intense effect on themselves, they chose to counterbalance it with discourse of sacrifice. Some parents mention the concept of sacrifice, namely dreams and personal goals that they have to sacrifice for raising their child with disability. Specifically, most of the parents describe stories of personal sacrifice, narratives where they sacrificed themselves, their social life, their professional status, they sacrificed themselves as a person over their child and their parental role. Thus, the two meanings could be interrelated in a way that could be described as: 'as long as I am responsible for that, I restore it through my sacrifice'.

The parents' meaning-making around responsibility is derived by the current social representations around parenting and disability within the local society but also by dominant medical and genetic ideas. The parental role in the local context is quite powerful, with parenting mainly characterized by overprotectiveness, even after adulthood. The parent, especially the mother, is primarily responsible for all aspects of the child's life, with no particular sharing of responsibility. On the other hand, disability carries very negative social representations, as explained above, and by extension parenting a child with disability is very negatively charged. Lastly, the parents' meaning-making around responsibility is derived by genetic ideas around heredity, in terms of the child genetically being a continuation of the parents, and what the child presents is indirectly part of the parent, carrying it in their body from the parents' body. This meaning-making effort is also derived from other medical ideas, such as how the fetus is affected in the mother's womb, if for example the mother experiences stressful situations during pregnancy, this has a direct impact on the fetus.

Overall, the parents construct meaning regarding their child's disability as their own responsibility. This meaning-making effort has a restorative function, through their sacrifice as individuals over their parental role of raising their children with developmental disabilities.

8.2.3. Parents' coping

This section focuses on the parents' psychological coping as revealed through this study. According to Valsiner (2007) people create and use meaning in order to cope in terms of actively adapting to the human socio-cultural context, to understand and move forward. Coping is approached as a meaning-making, socially-contextualized process, which allows the person to act within their world (Kadianaki, 2014). Thus, meaning-making is part of the individual’s system of organized psychological functions (Valsiner, 2007), a process derived from the need to cope in terms of psychological functioning. Zittoun (2006) suggests that people use symbolic resources to process transitions, which are followed by ruptures, in order to organize their psychological functioning and development (Zittoun, 2006).

In terms of psychological functioning, the parents of children with developmental disabilities are found to use particular ways of coping. Starting from the broader one, I discuss the use of meaning-making, continue to the use of concrete symbolic resources and I end up to other practical strategies as parents’ ways of coping.

A coping process broadly used by parents is meaning-making. As discussed in chapter 8.2.2., parents construct the meaning in order to understand and better relate with their experience of parenting their children with developmental disability. I suggest that meaning-making is a coping process as well. I will explore coping through the meaning-making effort of blessing.

Blessing is constructed as meaning by parents, reflecting reversely the burden and difficulty of raising a child with disabilities. The parents and their children may struggle in their everyday routine but by creating and using the meaning of blessing they find a way to replace the negative aspect of difficulties and to adopt an optimistic aspect of their everyday life. For example, parents reverse the burden with the blessing of finding the meaning of life. Additionally, parents discuss blessing as a meaning used daily and mainly as a response to the child's daily difficulties, which enables them to self develop but also to get shielded as individuals. This coping process is also about the daily rupture of the parenting experience. It is interesting to note that parents appear to need to develop efficient coping strategies to deal with the rupture of the everyday struggle of parenting a child with developmental disability. In this context, the parents create the meaning of blessing, use it in their everyday challenges with their child and feel shielded against the difficulties that they have to face. Therefore, the everyday difficulties enable the parents to construct the new meaning of blessing, other that the burden, to use it regarding these everyday difficulties and to cope with them by reversing their meaning.

Concerning the use of symbolic resources, I discuss the use of a blog and religion, starting from the blog. This is about an experiential blog, where a father of a child with Down syndrome, coming from a different socio-cultural milieu, posts stories, ideas and activities regarding the life of his child. The mother explains how following the blog changed her representation about Down syndrome, with the social representations she had until then being mainly negative. The blog offered her a more optimistic understanding of the syndrome, without unnecessary emotionality and projection of negative expectations, which are reflected from her immediate socio-cultural context. Most of all, though, the blog restored the mother's hope, displaying a hope story about a person with the syndrome who has the right to be happy, to enjoy life and to have a life worth living. Essentially, this blog, as a symbolic resource, helped the mother to mediate the prevailing negative representations she was confronted with when experienced the rupture of the birth of her child with Down syndrome. The rupture generated intense uncertainty, insecurity and stress. However, the use of the blog within the transitional period that followed the rupture, allowed the construction of new meaning regarding the syndrome, enabling her to negotiate the meaning of the diagnosis and finally to adopt a more hopeful perspective about her child's diagnosis.

To better understand the symbolic relation between the mother and the blog, I use Zittoun's semiotic prism (2007), which includes the person, the other, the symbolic element and the meaning, thus the mother as the user of the blog, the father who writes the blog, the blog as the symbolic object and the meaning of the blog for the mother. The other, namely the blogging father, and the experience of the other, which he shares through the blog, is present in the mother's meaning of the blog. This dimension of symbolic resources reveals two significant points. First, the use of the blog as a symbolic resource enables the mother to interact with a social other, who becomes present through the symbolic elements of the blog (obvious from the mothers' claim of feeling the child of the blogging father as her child as well). Second, the social-psychological nature of the mother's use of symbolic resources, such as the blog, reveals the dynamics between the inner and the social world (Zittoun, 2007). Zittoun's semiotic prism is further discussed in chapter 3.2.2.

Another symbolic resource widely used by parents is religion. Religious coping has several aspects, according to parents, with most of them using it as a moral support. The use of religion as a symbolic resource is adopted through prayer and pilgrimage. What is interesting is that religion functions as a conceptual symbolic resource: parents read the prayer or go to the monastery and eventually feel calmer. The effect of religious practice is not immediately evident but after a few days. In fact, religion seems to have a self-fulfilling function: parents use religion as a supportive practice and when something good happens, they attribute it to this practice. Essentially, religious practices allow the parent to mediate the daily ruptures that emerge from raising a child with developmental disability, offering a form of conceptualization regarding what is helpful and how to find support in their everyday routine problems. Additionally, the parents emphasize that they came closer to God due to the everyday ruptures of parenting their children, gaining strength from the resource of religion, which they describe as supernatural strength. Therefore, religion is a strong symbolic resource used by parents in order to intentionally deal with the child's everyday issues.

The levels of semiotic mediation (Zittoun, 2006), thus the different levels of the symbolic resources' generality, allow to better understand the symbolic resource of religion as used by parents. The first level is related to the immediate embodied perception, where the parents cannot define what exactly is helpful when going to the church or reading the prayer, that is their experience in the here-and-now remains unclear. At the second level of semiotic mediation, parents acknowledge religion as a helpful resource and their experience becomes somehow more specific, in terms of pursuing to go to the church as a relieving action, thus choosing a local conduct. The third level concerns the consolidation of this semiotic mediation, in this case of going to the church, into a specific regular behaviour. Finally, parents form a clear view of being helped by religious practices, including going to the church, which they consciously select (Zittoun, 2006).

Another important aspect of symbolic resources is time orientation. Zittoun (2006) suggests that symbolic resources are time oriented, because they enable people to generate continuity of self in times of uncertainty between past and present and move towards the future. In terms of time orientation, symbolic resources might be retrospective, meaning that their function is related to how they connect the person with something from the past, such as for example an album of family photos back in time. Symbolic resources might also be microgenetic, related to the here-and-now function of their use, such as for example an immigrant singing his home music to his new country, relating his past with the immediate future. Lastly, symbolic resources might also be future-directed, called prospective, where the symbolic resources aim towards the exploration of something new and unknown. The symbolic resource of religion, used by parents, is clearly oriented to the here-and-now of the parents' experience, allowing a connecting process between past and immediate future: the parents feel calm and relieved, by using a symbolic resource already present in their lives, that is derived from the past, comforting the present worries, such as the stress of the everyday challenges with the child, with their feelings escalating after some days, feeling eventually more empowered about the 'not that uncertain anymore' future.

Concerning the parents' practical strategies of coping, the most common out of them is peer support and learning. Many parents seek support from other parents in a similar situation, on their own initiative, as there is no organized form of state support. This support seems to function as a coping strategy for parents. According to Zittoun (2007), people are involved in social networks, where they activate others for their expertise or their relational support. Particularly, parents systematically pursue to meet other parents, from whom they draw strength, direction and hope. The peer support is described as revelatory, enabling the parents to move from the point of despair, of helplessness and hopelessness to the point of hope and relief of sharing. Peer support seems to mediate the rupture of the parenting experience, both during the early stages of their experience, when parents feel they need it more, as in the later stages when the parent is confronted with the rupture of parenting their children with developmental disabilities.

Zittoun (2007) claims that learning, along with meaning-making and identity process, is among the pivotal processes of the unit rupture-transition. Learning is used by parents as a coping strategy to obtain valuable knowledge and to find answers regarding the child's diagnosis. Reading books, reading in the Internet or involving in parents' associations is among the most common forms of learning for parents. Following the rupture of their children's diagnosis, parents encounter the uncertainty of their lack of knowledge about the diagnosis. They immediately start researching for informative sources, again on their own initiative. All the sources parents choose to enrich their knowledge regarding the child's diagnosis have in common that they discuss the experience of diagnosis of other people with similar conditions. They read books written by people with autism, stories of recognizable persons with Down syndrome or they pursue direct contact with families and children with the same diagnosis through their involvement with parents' associations. This targeted learning effort, as a coping strategy, relieves parents as they feel they share the experience of their own child's diagnosis with the experience they read, even to the point where they feel they know the person whose story they read. Parents feel safe through this experiential knowledge they obtain, mediating their inexperience and insecurity due to lack of knowledge on the diagnosis and enabling them to broadening their perspective in terms of educating themselves on the child's diagnosis and feel more prepared. Parents claim that the more informed they are, the more they limit their uncertainty.

8.2.4. Bringing it all together

Bringing together the concept of rupture, the meaning-making efforts and the coping processes that parents use, I close this chapter by focusing on the input of this study to the existing literature.

With regards to ruptures, Zittoun (2009) theorizes the concept at the level of microgenesis, as a total of many small changes, leading though to bigger scale changes and ontogenetic transformations, linking the micro and ontogenetic level of ruptures. Kadianaki (2010) introduces a stabilized form of ruptures, which is related with the emergence of repeated tensions during the life trajectories of immigrants experiencing relocation.

This study advances the concept of rupture to the idea of several interconnected levels of ruptures. At the beginning of their experience, parents are confronted with the rupture of the announcement of the diagnosis, creating a sudden imbalance and causing stress. The second level of rupture concerns the parents' long-term reception of the diagnosis, where they find themselves negotiating their relation with the diagnosis and experiencing great ambivalence. Finally, the parents appear to experience the rupture of the life-long parenting experience, concerning an internal existential rupture that the parents go through. All three levels of interconnected ruptures produce uncertainty, strongly related to the specific socio-cultural context of parents raising their children with developmental disabilities. My perspective is that the particular parenting experience, that of children with developmental disabilities, within the particular socio-cultural context, raises such texture and levels of ruptures, forming lifelong processes of ruptures. This approach on ruptures suggests that we may need to conceptualize different types of ruptures, some of which may be open-ended and life-long.

Concerning meaning-making, this study confirms the significance of ambivalence in the meaning making processes. Abbey & Valsiner (2005) first described the critical role of ambivalence in the production of meaning. They also introduced the term ambivalent life space, when the person's experiences are intense and at the same time push in different directions, which applies to material objects as well as to present and future perspective.

The parents' process of meaning-making reveals very opposing and at times conflicting meanings. The parents often adopt in their discourse the meaning of blessing, which, on the opposite direction, reflects the burden, the struggle and the trial to which they are subjected. Another meaning-making effort emerged is 'normalization': the parents make sense of their parenting experience as normal, as a different experience of normality, while at the same time they emphasize the difficulties and the non-normality of their child. Further, the meaning of responsibility is also prevalent: the parents focus on their own responsibility regarding the child's diagnosis – responsibility both due to an abstract dimension, i.e. heredity, but also due to explicit practical reasons, i.e. family planning or vaccination – while on the same time the parents describe and adopt a life of sacrifice, which has a restorative function related to their responsibility.

All these dipoles of opposing directions as parents' meaning-making processes represent successfully the ambivalence described by Abbey & Valsiner (2005). The pairs of opposite meanings signify the ambivalence – and probably the ambivalent life space – of the parents of children with developmental disabilities, where "increasing and decreasing levels of ambivalence construct a self-perpetuating process of meaning construction and emergence of signs" (Abbey & Valsiner, 2005; p. 5).

What I suggest here is that these ambivalent meanings on which parents draw on are meanings that permeate the socio-cultural milieu and constitute powerful representations about parenting, heredity, children and optimal development. It is important to critically interrogate these representations and find ways to address the ways they may exert pressure and stigma to parenting or on the contrary aid psychological transition and development.

Regarding coping, this study suggests the use of symbolic resources (following a blog and exercising religion), the construction and use of meaning (such as blessing, 'normalization' and responsibility) and other practical strategies (learning and peer support) used by parents of children with developmental disabilities in order to support their psychological functioning. These coping strategies has several functions, discussed in the previous section.

Literature often recommends solution-focused or individual coping for parents of children with disabilities. For example, previous research has focused on parents' coping, such as finding support, acquiring knowledge (Graungaard & Skov, 2007; Kuhaneck et al, 2010), sharing their experience (Kuhaneck et al, 2010; Pennebaker & Seagal, 1999), making personal time (Kuhaneck et al, 2010) or religious coping (Twoy et al, 2007; Hastings et al, 2005; Pargament et al, 1990). This kind of individual coping is often detached from the socio-cultural context of the parents' experience. Kadianaki in her study on the transformative effects on stigma, approaches coping as a meaning-making effort, as a socially situated process, through which individuals "transform the way they see themselves and act within their world" (Kadianaki, 2014; p. 125). Respectively, parents engage in meaning-making efforts, mediating and employing new meanings to their parenting experience, through which they deal with their thoughts, feelings and actions (Valsiner, 2001). Additionally, all psychological phenomena are strictly context and culturally dependent (Valsiner, 1998) as their processes do not consist repetitively mirroring of the world but actively constructing and construing in their psychological reality (Salvatore, 2012). Therefore, my aim was to take into consideration the context in which the parents' coping occur, to consider the continuous interaction between culture and individual in order to gain a deeper understanding on parents' coping.

Another addition to the literature is reading the parents' coping when raising children with developmental disabilities through the lens of the theory of symbolic resources. People, in order to enable coping processes and to deal with ruptures, they need and utilize symbolic resources (Zittoun, 2007). While discussing the quality of symbolic resources and likening mediation to a mountain trail, Zittoun et al (2003) describe symbolic resources as the 'waypoints' that ensure their way throughout the mountain and, thus, psychological functioning. Interestingly enough, parents themselves represent their experience as a mountain, which they find ways, symbolic resources or other, to climb over and over again. Thus, parents employ symbolic resources in order to mediate their transition provoked by the rupture of parenting a child with developmental disabilities, by developing particular throughs and actions – coping – during their parenting experience.

Consequently, this study suggests the addition of the perspective of parents' coping within their socio-cultural context, taking into consideration the use of symbolic resources, namely semiotic mediation, enabled by parents in the particular social milieu.

8.3. Practical implications

8.3.1. Parents' support

This study has shown in many ways the evident lack of parental support in the local context. Parents have chances of support only on their own initiative, mainly peer support, even by traveling abroad. Additionally, parents' response to group activities or support groups, such as the focus discussion group for this study, is very eager, which indicates their intense need to participate in such initiatives.

Specifically, this research suggests the launch of long-term support programs for parents, namely from the moment of the announcement and onwards. As I discussed in chapters 5, parents experience an ongoing process of negotiating the diagnosis. Moreover, their experience is not one-dimensional, not only positive or only negative but multi-dimensional, experiencing plethora of oppositional feelings and meanings (discussed in chapter 6.1, 6.2. & 6.4.1). This means that the parent's support should take into consideration the processes that the parents go through, embrace them and find ways to relieve them from anxiety or other distressing feelings along the way of their parenting experience. Most importantly, these support programs should take into consideration the texture of the experience and the particular feelings and meanings that parents relate to the diagnosis, as demonstrated by this study. By doing this, they will be more effective and tailored to the specific needs. Lastly, as I discussed in chapter 6.4.2., the contact between parents challenges the concept of normal, placing parents in the broader social context and giving them an active role. This contact between parents might result in reducing isolation and exclusion, in limiting the feeling of being stigmatised, but also in raising awareness within the wider population. Additionally, peer support is important in terms of empowering and giving voice to parents, when “the stories told about disability have been spoken by professional voices” (Smith, 1999; p. 118)

Understanding the parents’ experience contributes in valuable knowledge in order to develop suitable support and apply sufficient tailored interventions. Intervention programmes may include parents support groups, family-based or individual interventions, family and personal psychotherapeutic interventions where needed, continuous parents’ education and development. These interventions may cover a broad range of needs like support to understand the diagnosis, to make meaning and process the new information, to interact with their children with developmental disabilities, to develop selfcare strategies and to manage the rest of the family’s needs in relation to the child with disability (i.e. parents’ relationship, balanced parenting between the child with and their siblings without disabilities, how to talk to other members of the family for the diagnosis, etc.).

8.3.2. Professionals’ support and development

Throughout this study, the professionals’ lack of understanding was highly emphasized by parents. The interaction with professionals is usually a parent's first contact with their child's diagnosis. In chapter 5.4.2. I discussed the pivotal role of the diagnosis in how the parent's experience would proceed. Particularly, parents emphasize the lack of empathy shown by professionals, their inappropriate treatment (mainly non-professional) and the adoption of power position towards parents and several procedural problems, such as short duration of appointments. These reports are mainly about medical professionals and less about therapists or teachers.

The approach of professionals should primarily be about understanding the parents’ perspective on the matter. Thus, to address the above challenges, professionals should first be trained from scratch in empathy, ethics, good practice, social and medical models of disability. However, this training will not be successful if it is short-term, thus continuous training of professionals is recommended. As discussed in chapter 8.1.1, the approach of professionals should also include tools of understanding the experience of parents, the processes they go through and the way parents make sense of their experience, in order for professionals to be able to better understand and approach the parents' experience. The education of professionals can be informative or collaborative in nature, i.e. achieved through the development of 1-1 communication between the two with an emphasis on the quality of the parents' experience and not on the practical guidance towards the parents. The training of professionals could also be framed with the appropriate supervision, in order to create the space where they can discuss concerns regarding their practice. Additionally, a formal protocol – possibly different for each field of practice – should be established, which professionals can use as guidance in order to ensure the consistency, efficiency and quality of their practices. Another practical suggestion regarding the professionals, probably following their training and support, is the creation of peer support groups or alliances between professionals and parents. In this way, there can be a substantial exchange of opinions, thoughts, and suggestions, with an emphasis on parents' knowledge, which is often underestimated by professionals.

8.4. Limitations and future directions

In terms of limitations of this research, the first concerns the participants. Participating parents are characterized by a noticeable level of functionality, mainly in terms of parenting their children and dealing with the diagnosis requirements – such as assessments, therapies, follow-ups and more – with an obvious intention towards personal development and the search for the best possible solutions regarding the child. Of course, it is interesting to note that this turned out to occur aimlessly and was not targeted by the design of the research, simply the parents who showed interest to participate in this study all have in common a good level of functioning. However, a large part of parents of children with disabilities do not have these characteristics. Therefore, a limitation of this study is that it examines the parenting experience of a part of parents raising their children with developmental disability, those who maintain a significant level of functioning for themselves and their children.

Another limitation of this study is the approach of the experience of parents in a generalized view, interviewing parents of children with developmental disorders in general and not specifically parents of children with autism or intellectual disability or Down syndrome. Such a perspective would provide more detailed information on the meaning-making efforts, interpretation and coping of each group of parents regarding their children's specific diagnosis. For example, children with Down syndrome are found to be quite extrovert while children with autism present key challenges in social interaction (American Psychiatric Association, 2013), two completely opposing signs of their diagnoses directly related to the social context. This separate approach could illustrate any difference to the parent's understanding of the experience, the process of negotiating the diagnosis and the making-making process of their child's diagnosis.

Another limitation of this research is related to the comparative under-representation of fathers in this research. Although fathers participated in this study, while in other research they are not or they are underrepresented (Davison et al, 2016; 2017), they were nevertheless significantly fewer than mothers (8 fathers and 18 mothers). Although the qualitative methodology does not deal with the strict quantitative representativeness of the sample (discussed in chapter 4.2.1.), however, the participation of more fathers would shed more detailed light on the experience of raising children with disabilities from their own perspective. It is obvious that there are some gender differences in how they perceive, experience and make sense of this experience, such as the different involvement into the caring role, making it useful to highlight the fathers' experience in more detail.

Lastly, another significant limitation of this research is that it did not explore possible changes of parents’ identity. Parents brought up self-related issues, such as their loss of self, and social role issues, such as socializing and employment, during the interviews (see chapter 7). The parental identity concerns the identity as a parent, involving the level of commitment to the parenting role and the personal development regarding parenting issues. A more focused, systematic consideration of possible changes in the parental identity could contribute to examine issues of restructuring the parents' identity, as it is affected by their parental experience, probably at an ontogenetic level where changes concern the way of viewing oneself and in the roles, he or she assumes. Additionally, the better understanding of parents’ identity would allow to comprehend the relation between social representations and parents’ identity. Psaltis (2015, p. 73) claims that “social representations are evoked through the social identities asserted in the activity of individuals”. Overall, the exploration of parent’s identity issues would add significant aspects of understanding the parental experience, either as a future continuation of this research or in another future research attempt.

In terms of future directions, a future research should focus on approaching the professionals with whom the parents interact and brought them quite often in their narratives. The attempt to understand the experience from the perspective of professionals will highlight their own representations and meanings regarding their work with parents of children with developmental disorders. Approaching professionals should be done in the context of research that takes into account the socio-cultural context. Additionally, the approach of the perspective of professionals could be done using a dialogical methodology (Gillespie & Cornish, 2010), in order to exactly elucidate how the provision of support by professionals to parents is hindered or ultimately not possible.

Another future direction concerns the exploration of parents' resilience within the specific social context. Resilience is defined as the ability to withstand and recover from disruptive life experiences, involving dynamic processes of positive adaptation and development, within the context of significant adversity (Masten & Cicchetti, 2016; Walsh, 2016). These skills enable recovery and positive development from significant life challenges. As such a significant life event, it is interesting to examine how the parents of children with disabilities develop personal resilience, how they support it (for example, through the use of symbolic resources), through a socially situated understanding of resilience. Furthermore, most research on resilience concerns family resilience (Walsh, 2016; Hawley & DeHaan, 1996; Lietz, 2012; Patterson, 2002; Hawley & DeHaan, 1996; Masten & Monn, 2015), leaving a gap regarding resilience from the parents' individual perspective, while research in the Cypriot context is quite limited, indicating a gap in literature.

8.6. Final thoughts

The aim of this study was to explore the parents' experience of raising their children with developmental disabilities as a process of psychological development within the given sociocultural context. Particularly, I intended to examine the subjective meaning of parents experiencing their children's developmental disabilities. To achieve this purpose, I studied the experiences of 26 mothers and fathers regarding their parenting experience, with an emphasis on their meanings, feelings, resources and the self.

Parents allowed me to enter into the depths of their lives – some of them literally opened the doors and welcomed me into their houses – and unfolded the big picture of their experience, giving me access to very personal, intimate and deep thoughts and concerns. I doubt that they share this rich in meaning experience about what it's like to raise their different children within the specific, restrictive in many ways, socio-cultural environment, with other people. After hours of conversation during the interviews and the discussion groups and through laughters and tears and open sharing, we approached the parents' experience to a satisfactory degree. I hope that this thesis does justice to this experience. I admit that I am impressed by the loneliness that parents experience – personal, social and institutional – by the open wounds they carry and the determination with which they deal with their parenting experience. What I keep as a reflection to this day, is the great inconsistency between the parents' internalized experience and the external representation of this experience, namely what others understand that they experience. It is my wish that this research will contribute to bridging this gap, by allowing a comprehensive understanding of the experience of parents raising their children with developmental disabilities.

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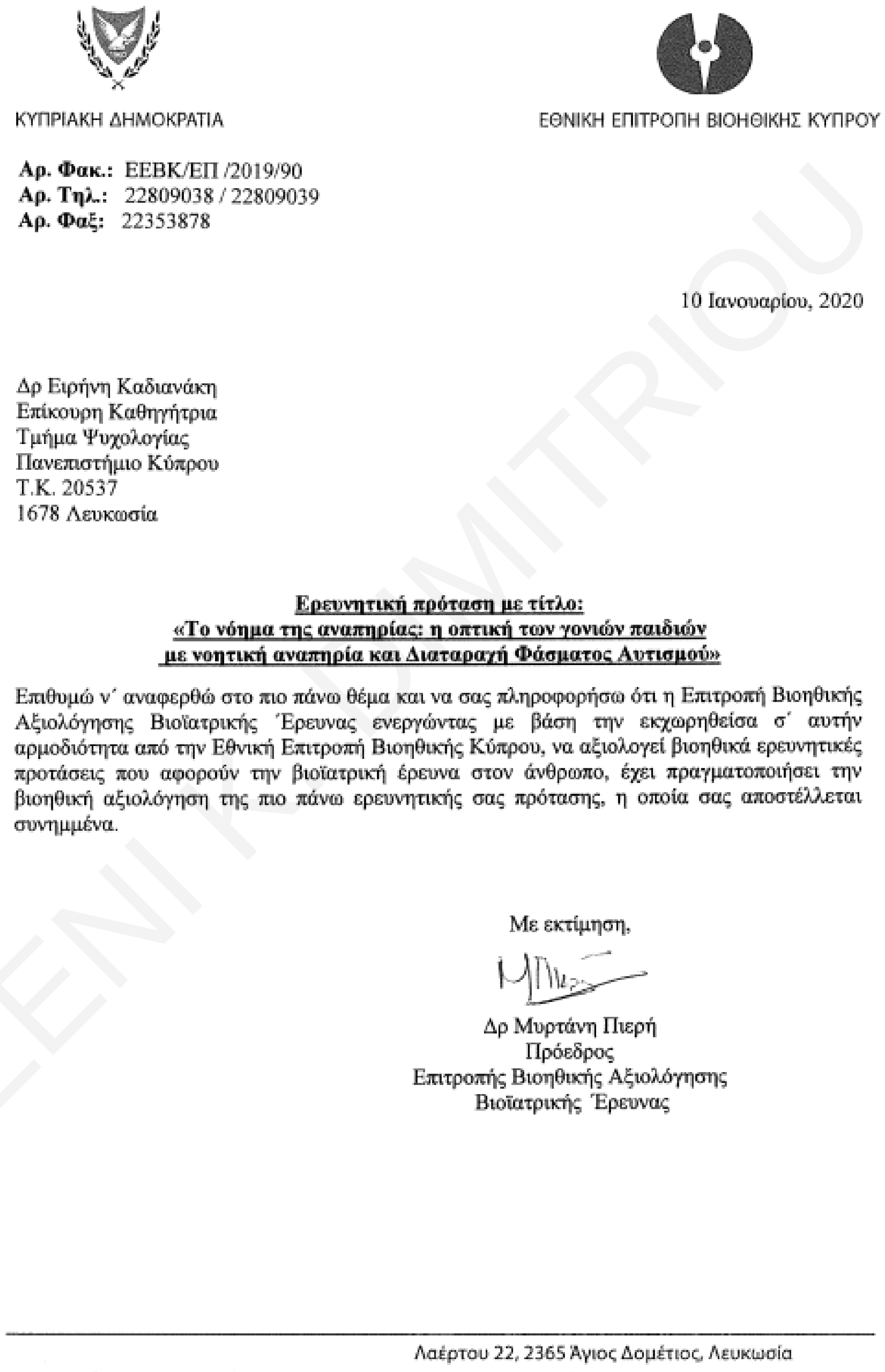
Appendices

Appendix A: Cyprus Bioethics Committee Approval



ΚΥΠΡΙΑΚΗ ΔΗΜΟΚΡΑΤΙΑ

ΕΘΝΙΚΗ ΕΠΙΤΡΟΠΗ ΒΙΟΗΘΙΚΗΣ ΚΥΠΡΟΥ

Αρ. Φακ.: ΕΕΒΚ/ΕΠ /2019/90
Αρ. Τηλ.: 22809038 / 22809039
Αρ. Φαξ: 22353878

10 Ιανουαρίου, 2020

Δρ Ειρήνη Καδιανάκη
Επίκουρη Καθηγήτρια
Τμήμα Ψυχολογίας
Πανεπιστήμιο Κύπρου
Τ.Κ. 20537
1678 Λευκωσία

Ερευνητική πρόταση με τίτλο:
«Το νόημα της αναπηρίας: η οπτική των γονιών παιδιών
με νοητική αναπηρία και Διαταραχή Φάσματος Αυτισμού»

Επιθυμώ ν΄ αναφερθώ στο πιο πάνω θέμα και να σας πληροφορήσω ότι η Επιτροπή Βιοηθικής Αξιολόγησης Βιοϊατρικής Έρευνας ενεργώντας με βάση την εκχωρηθείσα σ΄ αυτήν αρμοδιότητα από την Εθνική Επιτροπή Βιοηθικής Κύπρου, να αξιολογεί βιοηθικά ερευνητικές προτάσεις που αφορούν την βιοϊατρική έρευνα στον άνθρωπο, έχει πραγματοποιήσει την βιοηθική αξιολόγηση της πιο πάνω ερευνητικής σας πρότασης, η οποία σας αποστέλλεται συνημμένα.

Με εκτίμηση,

Δρ Μυρτάνη Πιερή
Πρόεδρος
Επιτροπής Βιοηθικής Αξιολόγησης
Βιοϊατρικής Έρευνας

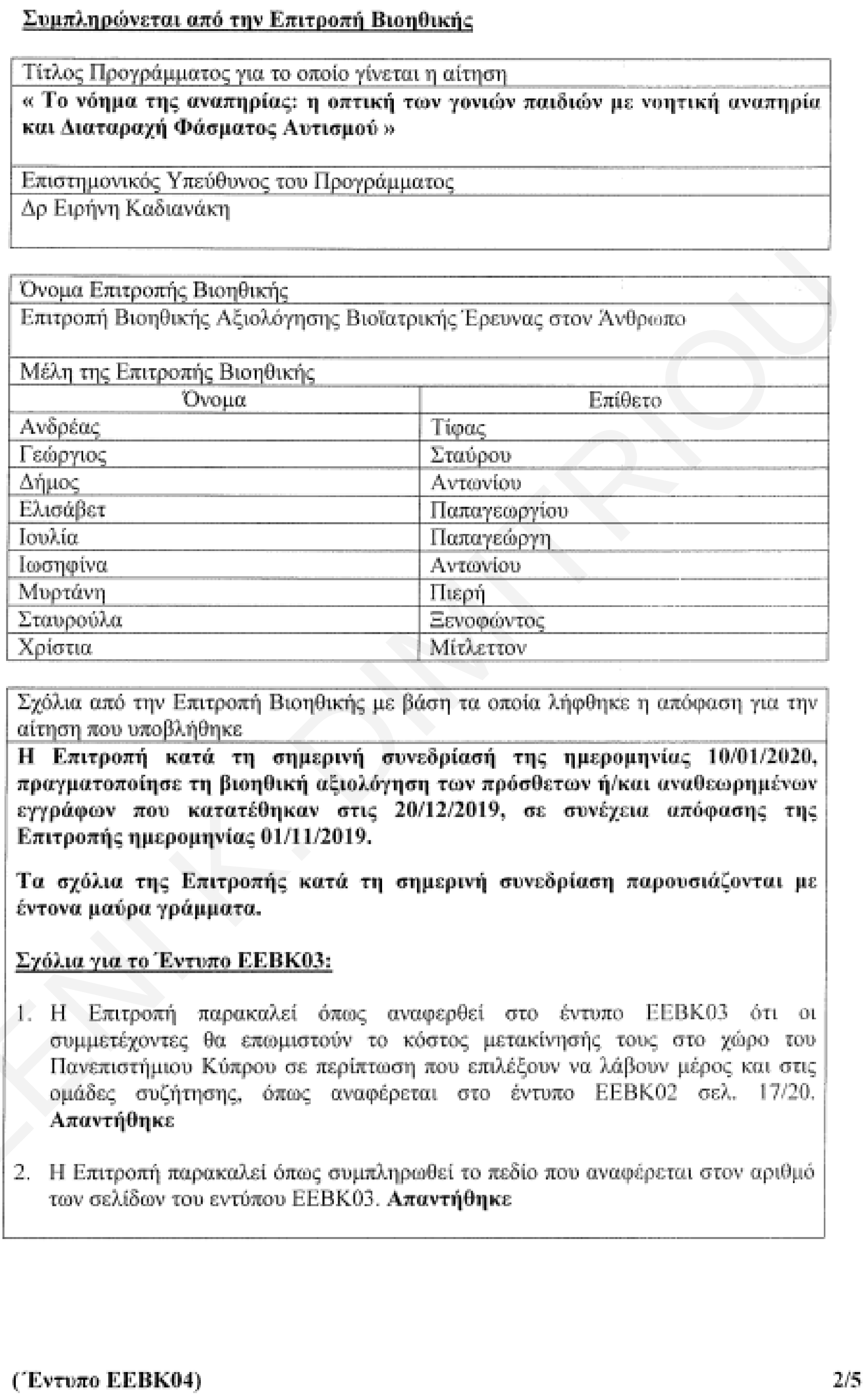
Λαέρτου 22, 2365 Άγιος Δομέτιος, Λευκωσία
Ηλεκτρονικό Ταχυδρομείο: cnbc@bioethics.gov.cy, Ιστοσελίδα: www.bioethics.gov.cy

ΕΕΒΚ/ΕΠ 2019/90

ΕΜΠΙΣΤΕΥΤΙΚΟ

ΑΠΟΦΑΣΗ
ΕΠΙΤΡΟΠΗΣ ΒΙΟΗΘΙΚΗΣ ΑΞΙΟΛΟΓΗΣΗΣ
ΓΙΑ
ΕΓΚΡΙΣΗ Ή ΑΠΟΡΡΙΨΗ
ΠΡΟΓΡΑΜΜΑΤΟΣ

Η απόφαση της Επιτροπής Βιοηθικής Αξιολόγησης (ΕΒΑ) θα πρέπει να κοινοποιηθεί προς την Εθνική Επιτροπή Βιοηθικής Κύπρου μαζί με όλα τα υπόλοιπα έντυπα που αφορούν το πρόγραμμα για το οποίο λήφθηκε σχετική απόφαση.



Συμπληρώνεται από την Επιτροπή Βιοηθικής

Τίτλος Προγράμματος για το οποίο γίνεται η αίτηση
« Το νόημα της αναπηρίας: η οπτική των γονιών παιδιών με νοητική αναπηρία και Διαταραχή Φάσματος Αυτισμού »
Επιστημονικός Υπεύθυνος του Προγράμματος
Δρ Ειρήνη Καδιανάκη

Όνομα Επιτροπής Βιοηθικής
Επιτροπή Βιοηθικής Αξιολόγησης Βιοϊατρικής Έρευνας στον Άνθρωπο
Μέλη της Επιτροπής Βιοηθικής

Όνομα	Επίθετο
Ανδρέας	Τίφας
Γεώργιος	Σταύρου
Δήμος	Αντωνίου
Ελισάβετ	Παπαγεωργίου
Ιουλία	Παπαγεώργη
Ιωσηφίνα	Αντωνίου
Μυρτάνη	Πιερή
Σταυρούλα	Ξενοφώντος
Χρίστια	Μίτλεττον

Σχόλια από την Επιτροπή Βιοηθικής με βάση τα οποία λήφθηκε η απόφαση για την αίτηση που υποβλήθηκε

Η Επιτροπή κατά τη σημερινή συνεδρίασή της ημερομηνίας 10/01/2020, πραγματοποίησε τη βιοηθική αξιολόγηση των πρόσθετων ή/και αναθεωρημένων εγγράφων που κατατέθηκαν στις 20/12/2019, σε συνέχεια απόφασης της Επιτροπής ημερομηνίας 01/11/2019.

Τα σχόλια της Επιτροπής κατά τη σημερινή συνεδρίαση παρουσιάζονται με έντονα μαύρα γράμματα.

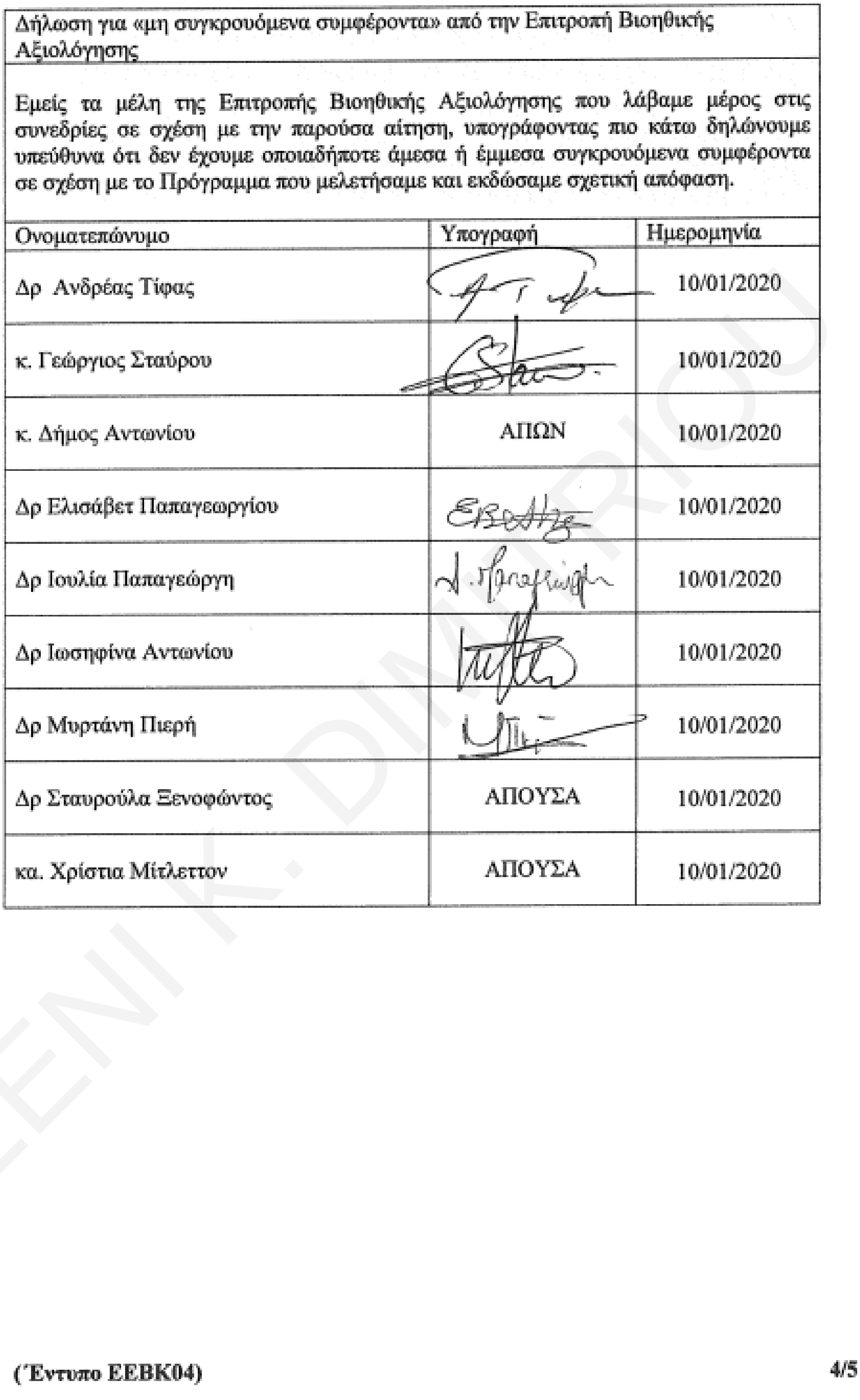
Σχόλια για το Έντυπο ΕΕΒΚ03:

1. Η Επιτροπή παρακαλεί όπως αναφερθεί στο έντυπο ΕΕΒΚ03 ότι οι συμμετέχοντες θα επωμιστούν το κόστος μετακίνησής τους στο χώρο του Πανεπιστήμιου Κύπρου σε περίπτωση που επιλέξουν να λάβουν μέρος και στις ομάδες συζήτησης, όπως αναφέρεται στο έντυπο ΕΕΒΚ02 σελ. 17/20. **Απαντήθηκε**
2. Η Επιτροπή παρακαλεί όπως συμπληρωθεί το πεδίο που αναφέρεται στον αριθμό των σελίδων του εντύπου ΕΕΒΚ03. **Απαντήθηκε**

Συμπληρώνεται από την Επιτροπή Βιοηθικής Αξιολόγησης

Στοιχεία	ΝΑΙ	ΟΧΙ
Βιογραφικά Στοιχεία ΟΛΩΝ των ερευνητών και των συνεργατών τους		√
Δήλωση μη συγκρουόμενων συμφερόντων	√	
Περιγραφή του είδους του Προγράμματος	√	
Περιγραφή του πληθυσμού που θα μελετηθεί	√	
Ο τρόπος με τον οποίο θα στρατολογηθούν άτομα για το Πρόγραμμα	√	
Μελετήθηκαν προσεκτικά τα έντυπα συγκατάθεσης (ΕΕΒΚ03);	√	
Τα έντυπα που θα χρησιμοποιηθούν για την στρατολόγηση ατόμων	√	
Ολόκληρο το πρωτόκολλο του Προγράμματος	√	
Δικαιολόγηση για την χρήση εικονικής φαρμακευτικής αγωγής	ΔΙ	
Υπεύθυνη δήλωση από όλους τους ερευνητές και συνεργάτες τους ότι τα έντυπα πληροφόρησης και συναίνεσης τους δεσμεύουν	√	
Διασφάλιση της προστασίας των δεδομένων που αφορούν τα άτομα που θα λάβουν μέρος στο Πρόγραμμα	√	
Λεπτομέρειες για την χρηματοδότηση του Προγράμματος	√	
Έχουν εκδοθεί ειδικά συμβόλαια σε σχέση με αμοιβές ;		√
Θα δίδονται αμοιβές στα άτομα που θα συμμετάσχουν στο Πρόγραμμα ;		√
Θα υπάρξουν οποιεσδήποτε οικονομικές επιβαρύνσεις για τα άτομα που θα συμμετάσχουν στο Πρόγραμμα ;		√
Οι ερευνητές ή/και συνεργάτες τους θα παίρνουν αμοιβές ;		√
Έχουν περιγραφεί τα αναμενόμενα οφέλη του Προγράμματος ;	√	
Έχει διαφανεί ότι προκύπτουν οποιαδήποτε οφέλη προς τον χρηματοδότη, τους ερευνητές και τους συνεργάτες τους από το Πρόγραμμα ;	√	
Εάν πιο πάνω είναι ΝΑΙ, να εξηγηθεί: Δημοσιεύσεις	√	
Έχουν τεκμηριωθεί όλες οι διευθετήσεις που έγιναν σε σχέση με τις υπηρεσίες που τυχόν θα παρασχεθούν για το Πρόγραμμα ;	√	
Θα υπάρχει συνεχής ενημέρωση για την ασφάλεια των ατόμων που θα λαμβάνουν μέρος στο Πρόγραμμα ;	√	
Υπάρχουν διαδικασίες για την υποβολή παραπόνων/καταγγελιών;	√	
Διασφαλίζονται επαρκώς τα δικαιώματα των ερευνητών για τις δημοσιεύσεις των αποτελεσμάτων ;	√	
Έχει δεσμευθεί ο/η Επιστημονικός Υπεύθυνος ότι δεν θα γίνουν οποιεσδήποτε αλλαγές στο Πρόγραμμα από την ημέρα που θα εγκριθεί από την Επιτροπή Βιοηθικής ;	√	

***Αποτελεί ευθύνη της Επιτροπής Βιοηθικής Αξιολόγησης να σταθμίσει όλα τα στοιχεία που έχουν δοθεί, να δώσει την απαραίτητη βαρύτητα εκεί που χρειάζεται και να λάβει απόφαση ως προς το κατά πόσον έχουν δοθεί ικανοποιητικές επεξηγήσεις σε σχέση με το προτεινόμενο Πρόγραμμα.**

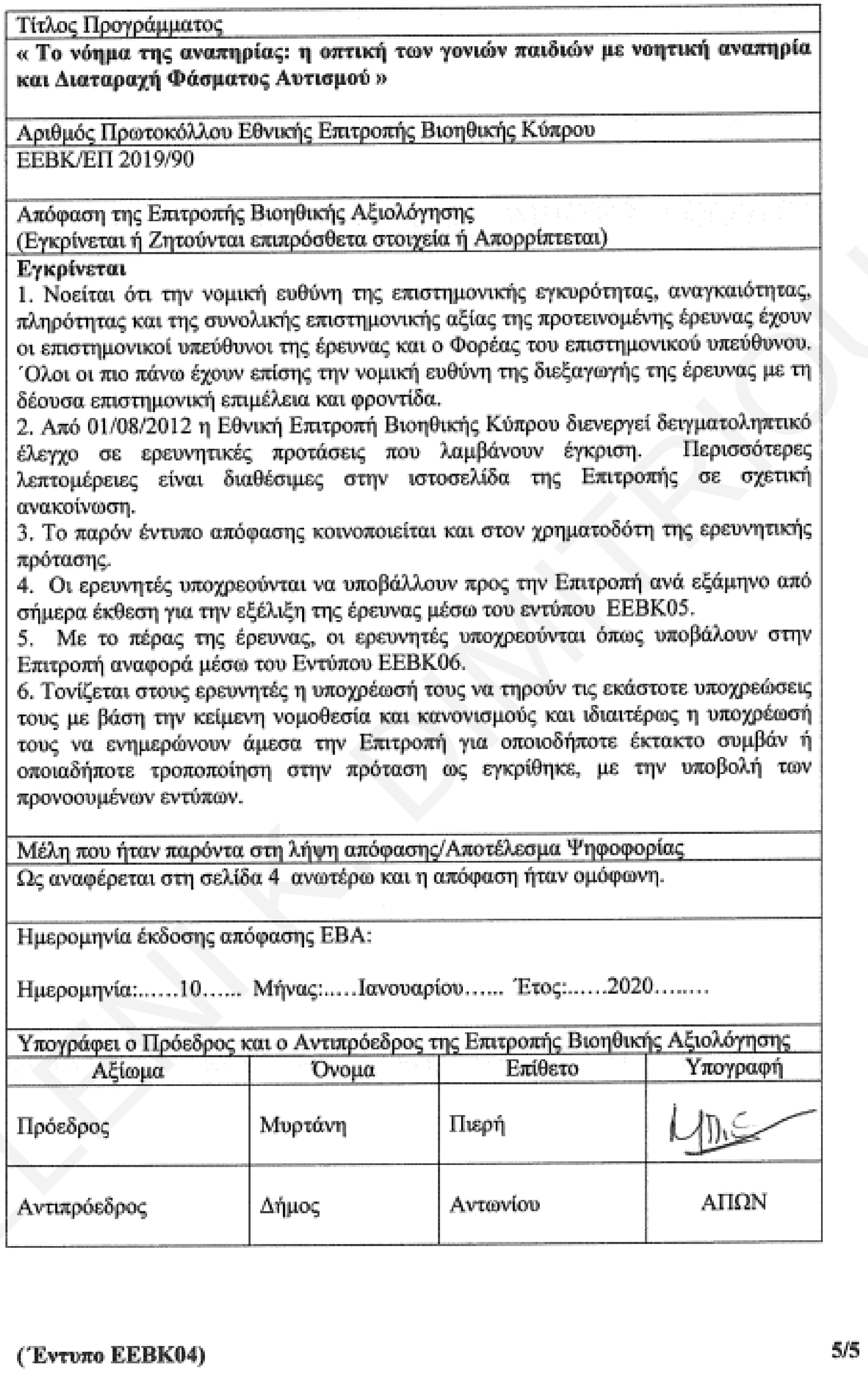


Δήλωση για «μη συγκρουόμενα συμφέροντα» από την Επιτροπή Βιοηθικής Αξιολόγησης

Εμείς τα μέλη της Επιτροπής Βιοηθικής Αξιολόγησης που λάβαμε μέρος στις συνεδρίες σε σχέση με την παρούσα αίτηση, υπογράφοντας πιο κάτω δηλώνουμε υπεύθυνα ότι δεν έχουμε οποιαδήποτε άμεσα ή έμμεσα συγκρουόμενα συμφέροντα σε σχέση με το Πρόγραμμα που μελετήσαμε και εκδώσαμε σχετική απόφαση.

Ονοματεπώνυμο	Υπογραφή	Ημερομηνία
Δρ Ανδρέας Τίφας		10/01/2020
κ. Γεώργιος Σταύρου		10/01/2020
κ. Δήμος Αντωνίου	ΑΠΩΝ	10/01/2020
Δρ Ελισάβετ Παπαγεωργίου		10/01/2020
Δρ Ιουλία Παπαγεώργη		10/01/2020
Δρ Ιωσηφίνα Αντωνίου		10/01/2020
Δρ Μυρτάνη Πιερή		10/01/2020
Δρ Σταυρούλα Ξενοφώντος	ΑΠΟΥΣΑ	10/01/2020
κα. Χρίστια Μίτλεττον	ΑΠΟΥΣΑ	10/01/2020

(Έντυπο ΕΕΒΚ04) **4/5**



Τίτλος Προγράμματος

« Το νόημα της αναπηρίας: η οπτική των γονιών παιδιών με νοητική αναπηρία και Διαταραχή Φάσματος Αυτισμού »

Αριθμός Πρωτοκόλλου Εθνικής Επιτροπής Βιοηθικής Κύπρου

ΕΕΒΚ/ΕΠ 2019/90

Απόφαση της Επιτροπής Βιοηθικής Αξιολόγησης
(Εγκρίνεται ή Ζητούνται επιπρόσθετα στοιχεία ή Απορρίπτεται)

Εγκρίνεται

1. Νοείται ότι την νομική ευθύνη της επιστημονικής εγκυρότητας, αναγκαιότητας, πληρότητας και της συνολικής επιστημονικής αξίας της προτεινομένης έρευνας έχουν οι επιστημονικοί υπεύθυνοι της έρευνας και ο Φορέας του επιστημονικού υπεύθυνου. ΄Ολοι οι πιο πάνω έχουν επίσης την νομική ευθύνη της διεξαγωγής της έρευνας με τη δέουσα επιστημονική επιμέλεια και φροντίδα.
2. Από 01/08/2012 η Εθνική Επιτροπή Βιοηθικής Κύπρου διενεργεί δειγματοληπτικό έλεγχο σε ερευνητικές προτάσεις που λαμβάνουν έγκριση. Περισσότερες λεπτομέρειες είναι διαθέσιμες στην ιστοσελίδα της Επιτροπής σε σχετική ανακοίνωση.
3. Το παρόν έντυπο απόφασης κοινοποιείται και στον χρηματοδότη της ερευνητικής πρότασης.
4. Οι ερευνητές υποχρεούνται να υποβάλλουν προς την Επιτροπή ανά εξάμηνο από σήμερα έκθεση για την εξέλιξη της έρευνας μέσω του εντύπου ΕΕΒΚ05.
5. Με το πέρας της έρευνας, οι ερευνητές υποχρεούνται όπως υποβάλουν στην Επιτροπή αναφορά μέσω του Εντύπου ΕΕΒΚ06.
6. Τονίζεται στους ερευνητές η υποχρέωσή τους να τηρούν τις εκάστοτε υποχρεώσεις τους με βάση την κείμενη νομοθεσία και κανονισμούς και ιδιαιτέρως η υποχρέωση τους να ενημερώνουν άμεσα την Επιτροπή για οποιοδήποτε έκτακτο συμβάν ή οποιαδήποτε τροποποίηση στην πρόταση ως εγκρίθηκε, με την υποβολή των προνοουμένων εντύπων.

Μέλη που ήταν παρόντα στη λήψη απόφασης/Αποτέλεσμα Ψηφοφορίας

Ως αναφέρεται στη σελίδα 4 ανωτέρω και η απόφαση ήταν ομόφωνη.

Ημερομηνία έκδοσης απόφασης ΕΒΑ:

Ημερομηνία:……10…... Μήνας:…..Ιανουαρίου…... Έτος:……2020…..…

Υπογράφει ο Πρόεδρος και ο Αντιπρόεδρος της Επιτροπής Βιοηθικής Αξιολόγησης

Αξίωμα	Όνομα	Επίθετο	Υπογραφή
Πρόεδρος	Μυρτάνη	Πιερή	
Αντιπρόεδρος	Δήμος	Αντωνίου	ΑΠΩΝ

(Έντυπο ΕΕΒΚ04) **5/5**

Appendix B: Consent Form for interviews / focus group

ΕΝΤΥΠΑ ΣΥΓΚΑΤΑΘΕΣΗΣ

για συμμετοχή σε ερευνητικό πρόγραμμα

(Τα έντυπα αποτελούνται συνολικά από 10 σελίδες)

Τίτλος του Προγράμματος στο οποίο καλείστε να συμμετάσχετε

Το νόημα της αναπηρίας: Η οπτική των γονιών παιδιών με νοητική αναπηρία και Διαταραχή Φάσματος Αυτισμού. (Making sense of disability: The perspective of parents of children with intellectual disability and ASD)

Στο έντυπο αυτό δίνονται εξηγήσεις σε απλή και κατανοητή γλώσσα σχετικά με το τι ζητείται από εσάς ή/και τι θα συμβεί σε εσάς, εάν συμφωνήσετε να συμμετάσχετε στο πρόγραμμα:

1. Περιγράφονται οποιοιδήποτε κίνδυνοι μπορεί να υπάρξουν ή ταλαιπωρία που τυχόν θα υποστείτε από την συμμετοχή σας στο πρόγραμμα.
2. Επεξηγείται με κάθε λεπτομέρεια ποιος ή ποιοι θα έχουν πρόσβαση στα δεδομένα που σας αφορούν και θα προκύψουν από το πρόγραμμα που θα συμμετάσχετε ή/και άλλο υλικό/δεδομένα που εθελοντικά θα δώσετε για το πρόγραμμα.
3. Δίνεται η χρονική περίοδος για την οποία οι υπεύθυνοι του προγράμματος θα έχουν πρόσβαση στις πληροφορίες ή/και υλικό σας αφορά.
4. Επεξηγείται το τί ευελπιστούν να μάθουν οι υπεύθυνοι του προγράμματος σαν αποτέλεσμα και της δικής σας συμμετοχής.
5. Δίνεται μία εκτίμηση για το όφελος που μπορεί να υπάρξει για τους ερευνητές ή/και χρηματοδότες αυτού του προγράμματος.
6. **Δεν πρέπει να συμμετάσχετε, εάν δεν επιθυμείτε ή εάν έχετε οποιουσδήποτε ενδοιασμούς που αφορούν τη συμμετοχή σας στο πρόγραμμα.**
7. Εάν αποφασίσετε να συμμετάσχετε, πρέπει να αναφέρετε εάν είχατε συμμετάσχει σε οποιοδήποτε άλλο πρόγραμμα έρευνας μέσα στους τελευταίους 12 μήνες.
8. Εάν αποφασίσετε να μην συμμετάσχετε και είστε ασθενής, η θεραπεία σας δεν θα επηρεαστεί από την απόφασή σας.
9. **Είστε ελεύθεροι να αποσύρετε οποιαδήποτε στιγμή εσείς επιθυμείτε τη συγκατάθεση για την συμμετοχή σας στο πρόγραμμα.**
10. Εάν είστε ασθενής, η απόφασή σας να αποσύρετε την συγκατάθεση σας, δεν θα έχει οποιεσδήποτε επιπτώσεις στη θεραπεία σας.
11. Πρέπει όλες οι σελίδες των εντύπων συγκατάθεσης να φέρουν το ονοματεπώνυμο και την υπογραφή σας.

Επιστημονικός υπεύθυνος του Προγράμματος στο οποίο καλείστε να συμμετάσχετε

Δρ. Ειρήνη Καδιανάκη, Επίκουρη Καθηγήτρια, Τμήμα Ψυχολογίας, Πανεπιστήμιο Κύπρου (Ηλεκτρονικό Ταχυδρομείο: kadianaki.irini@ucy.ac.cy, Τηλέφωνο: 22892063)

Επίθετο:		Όνομα:	
Υπογραφή:		Ημερομηνία:	
Χρονική διάρκεια του Προγράμματος:			

Δύο χρόνια μετά την λήψη έγκρισης από τη Βιοηθική Επιτροπή

Δίδετε συγκατάθεση για τον εαυτό σας ή για κάποιο άλλο άτομο;	
Εάν πιο πάνω απαντήσατε για κάποιον άλλο, τότε δώσετε λεπτομέρειες και το όνομα του.	

Ερώτηση	NAI ή OXI
Συμπληρώσατε τα έντυπα συγκατάθεσης εσείς προσωπικά;	
Τους τελευταίους 12 μήνες έχετε συμμετάσχει σε οποιοδήποτε άλλο ερευνητικό πρόγραμμα;	
Διαβάσατε και καταλάβατε τις πληροφορίες για ασθενείς ή/και εθελοντές;	
Είχατε την ευκαιρία να ρωτήσετε ερωτήσεις και να συζητήσετε το Πρόγραμμα;	
Δόθηκαν ικανοποιητικές απαντήσεις και εξηγήσεις στα τυχόν ερωτήματά σας;	
Καταλαβαίνετε ότι μπορείτε να αποσυρθείτε από το πρόγραμμα, όποτε θέλετε;	
Καταλαβαίνετε ότι, εάν αποσυρθείτε, δεν είναι αναγκαίο να δώσετε οποιεσδήποτε εξηγήσεις για την απόφαση που πήρατε;	
(Για ασθενείς) καταλαβαίνετε ότι, εάν αποσυρθείτε, δεν θα υπάρξουν επιπτώσεις στην τυχόν θεραπεία που παίρνετε ή που μπορεί να πάρετε μελλοντικά;	
Συμφωνείτε να συμμετάσχετε στο πρόγραμμα;	
Με ποιόν υπεύθυνο μιλήσατε;	

Επίθετο:		Όνομα:	
Υπογραφή:		Ημερομηνία:	
Σύντομη περιγραφή του προγράμματος (διαδικασίες και σκοπός).			
Η έρευνα αυτή στοχεύει να μελετήσει πως οι γονείς αντιλαμβάνονται την αναπτυξιακή διαταραχή του παιδιού τους, ποιο νόημα της δίνουν και πως αυτό τους επηρεάζει. Επιπλέον, αναμένεται να μελετηθεί πως αυτή η ερμηνεία επιδρά στην αποδοχή της νοητικής αναπηρίας και πως συνδέεται με τη δράση τους ως γονείς παιδιού με νοητική αναπηρία ή/και αναπτυξιακές διαταραχές.			

Στην έρευνα αυτή συμμετέχουν γονείς παιδιών με διάφορες μορφές νοητικής αναπηρίας ή/και αναπτυξιακών διαταραχών από όλες τις πόλεις και τις επαρχίες της Κύπρου. Η διαδικασία περιλαμβάνει ατομικές συνεντεύξεις και ομάδες συζήτησης.

Με τη συμμετοχή σας σε αυτή την έρευνα θα συμβάλλετε στη μελέτη της κατανόησης και της αποδοχής της νοητικής αναπηρίας από τους γονείς παιδιών με νοητική αναπηρία. Ωστόσο, η έρευνα αυτή ίσως αποτελέσει τη βάση για την εξεύρεση αποτελεσματικότερων τρόπων στήριξης των γονιών προς όφελος των οικογενειών.

Η έρευνα αυτή αποτελεί μέρος της διδακτορικής διατριβής της ερευνήτριας (Ελένη Δημητρίου) για την ολοκλήρωση του Διδακτορικού Προγράμματος Κλινικής Ψυχολογίας του Πανεπιστημίου Κύπρου, στο οποίο φοιτά.

Λεπτομέρειες του τι θα ζητηθεί ή/και τι θα συμβεί στους συμμετέχοντες στο πρόγραμμα.

Αρχικά θα σας ζητηθεί να συμπληρώσετε το έντυπο συγκατάθεσης (αυτό που κρατάτε στα χέρια σας). Σε περίπτωση που αποφασίσετε να συμμετάσχετε στην έρευνα, θα ερωτηθείτε αν επιθυμείτε να συμμετάσχετε στις ατομικές συνεντεύξεις και στις ομάδες συζήτησης ή μόνο στις ατομικές συνεντεύξεις. Θα ενημερωθείτε εξ αρχής ότι η συνέντευξη θα πραγματοποιηθεί στο χώρο σας (σπίτι) εφόσον συμφωνείτε και εφόσον πληροί τα απαραίτητα κριτήρια (εμπιστευτικότητα, ησυχία). Σε περίπτωση που δεν επιθυμείτε κάτι τέτοιο, η συνέντευξη θα πραγματοποιηθεί σε άλλο χώρο που θα συμφωνηθεί μεταξύ μας (πιθανότατα στο Πανεπιστήμιο Κύπρου). Η ομάδα συζήτησης θα πραγματοποιηθεί σε αίθουσα του Πανεπιστημίου Κύπρου ή σε άλλο ουδέτερο χώρο. Το κόστος μετακίνησης από και προς το Πανεπιστήμιο Κύπρου αναλαμβάνεται από τους ίδιους τους συμμετέχοντες.

Όσον αφορά τη συνέντευξη, θα οριστεί ημέρα και ώρα που θα πραγματοποιηθεί η συνέντευξη, διάρκειας περίπου 90 λεπτών. Οι πρώτες ερωτήσεις της συνέντευξης αφορούν την καταγραφή δημογραφικών στοιχείων και στοιχείων επικοινωνίας. Οι υπόλοιπες ερωτήσεις της συνέντευξης αφορούν το πως κατανοείτε την εμπειρία να μεγαλώνετε ένα παιδί με αναπηρία, πως σας επηρεάζει, τι πιστεύετε για αυτή την εμπειρία και πως ενεργείτε στη ζωή σας με αυτό το δεδομένο. Μπορείτε να δώσετε όσες πληροφορίες επιθυμείτε και νιώθετε άνετα να μοιραστείτε. Μπορείτε, επίσης, να μην απαντήσετε κάποια/ες ερώτηση/εις και δε χρειάζεται να εξηγήσετε γιατί. Κατά τη διάρκεια της συνέντευξης, αν (συνεχίζεται) χρειαστείτε διάλειμμα μπορείτε να το ζητήσετε. Επιπλέον, αν επιθυμείτε να μη συνεχίσετε και να διακοπεί η συνέντευξη μπορείτε να το ζητήσετε χωρίς να χρειάζεται να δώσετε κάποια εξήγηση. Σε αυτή την περίπτωση, θα αποσύρετε τη συγκατάθεση που δώσατε χωρίς οποιαδήποτε συνέπεια. Η συνέντευξη θα διεξαχθεί από την ερευνήτρια (Ελένη Δημητρίου) και θα ηχογραφείται.

Σε περίπτωση που αποφασίσετε να συμμετάσχετε και σε ομάδα συζήτησης, διάρκειας περίπου 90 λεπτών, θα σας ζητηθεί να επιλέξετε μία από τις προτεινόμενες ημέρες και ώρες διεξαγωγής της ομάδας. Η ερευνήτρια (Ελένη Δημητρίου) θα έχει ρόλο συντονιστή στην ομάδα συζήτησης, προσπαθώντας να διευκολύνει τη συζήτηση μεταξύ των συμμετεχόντων αλλά και να μοιραστεί εξίσου ο χρόνος σε όλους τους συμμετέχοντες. Η θεματολογία της ομάδας θα είναι παρόμοια με τη θεματολογία των ατομικών συνεντεύξεων, με τη μόνη διαφορά ότι θα υπάρχει η δυνατότητα ανταλλαγής απόψεων μεταξύ των μελών της ομάδας. Μπορείτε να δώσετε όσες πληροφορίες επιθυμείτε και νιώθετε άνετα να μοιραστείτε. Μπορείτε, επίσης, να μην απαντήσετε κάποια/ες ερώτηση/εις και δε χρειάζεται να εξηγήσετε γιατί. Επιπλέον, αν επιθυμείτε να μη συνεχίσετε, μπορείτε να αποχωρήσετε από την ομάδα, χωρίς να χρειάζεται να δώσετε κάποια εξήγηση. Σε αυτή την περίπτωση, θα αποσύρετε τη συγκατάθεση που δώσατε χωρίς οποιαδήποτε συνέπεια. Η ομάδα συζήτησης θα ηχογραφείται.

Όλες οι πληροφορίες που θα δώσετε θα είναι εμπιστευτικές, δηλαδή δε θα κοινοποιηθούν σε κανέναν άλλο. Στην περίπτωση που, κατά τη διάρκεια της συνέντευξης ή της ομάδας συζήτησης, νιώσετε δυσφορία ή ενοχληθείτε από κάποια ερώτηση, μπορείτε να απευθυνθείτε στις δημόσιες/κοινοτικές δομές συμβουλευτικών υπηρεσιών που προτείνονται (θα σας δοθεί λίστα με στοιχεία επικοινωνίας). Σε οποιαδήποτε φάση του ερευνητικού προγράμματος θα έχετε τη δυνατότητα να επικοινωνήσετε με την ερευνήτρια (Ελένη Δημητρίου) ή την επιστημονική υπεύθυνη (Δρ. Ειρήνη Καδιανάκη) για οποιοδήποτε ερώτημα ή ζήτημα που σας απασχολεί σχετικά με την έρευνα.

Λεπτομέρειες της χρηματοδότησης του ερευνητικού προγράμματος.

Δε χρειάζεται οποιαδήποτε χρηματοδότηση του ερευνητικού προγράμματος.

Λεπτομέρειες οποιονδήποτε κινδύνων που πιθανόν να υπάρξουν ή ταλαιπωρία που τυχόν θα υποστούν οι συμμετέχοντες στο πρόγραμμα.

Το θέμα που θα συζητηθεί τόσο στις ατομικές συνεντεύξεις όσο και στις ομάδες συζήτησης είναι ιδιαίτερα ευαίσθητο για εσάς. Έτσι, υπάρχει περίπτωση να νιώσετε (συνεχίζεται) κάποια δυσφορία ή κάποια έντονα συναισθήματα. Σε αυτή την περίπτωση, κατά τη διάρκεια της ατομικής συνέντευξης, μπορείτε να ζητήσετε ένα μικρό διάλειμμα μέχρι να νιώσετε έτοιμοι ξανά να συνεχιστεί η συνέντευξη. Κατά τη διάρκεια της συνέντευξης και της ομάδας συζήτησης, μπορείτε να μην απαντήσετε συγκεκριμένες ερωτήσεις ή/και να αποχωρήσετε σε οποιοδήποτε σημείο από την έρευνα. Αν συμβεί κάτι τέτοιο, δε χρειάζεται να εξηγήσετε τί ήταν εκείνο που σας έκανε να αποφασίσετε κάτι τέτοιο. Επιπλέον, θα σας δοθεί λίστα με τα ονόματα και τα στοιχεία επικοινωνίας εγγεγραμμένων ψυχολόγων και δημόσιων/κοινοτικών συμβουλευτικών υπηρεσιών όπου μπορείτε να αποταθείτε σε περίπτωση δυσφορίας ή αν θελήσετε να εξετάσετε τα έντονα συναισθήματα που προέκυψαν κατά τη διάρκεια της συμμετοχής σας στην έρευνα. Τέλος, ενδεχομένως να υπάρξει μικρή ταλαιπωρία κατά τη μετακίνησή σας προς και από το χώρο διεξαγωγής της ομάδας συζήτησης. Οι ομάδες θα διεξαχθούν σε προκαθορισμένη αίθουσα του Πανεπιστημίου Κύπρου, στην Πανεπιστημιούπολη στην Αγλαντζιά.

Λεπτομέρειες για το ποιες πληροφορίες ή/και τι υλικό θα συλλεγεί στα πλαίσια του προγράμματος, ποιος/ποιοι θα έχουν πρόσβαση σε αυτά και για πόσο χρονικό διάστημα.

Οι πληροφορίες που θα συλλεγούν στα πλαίσια αυτού του ερευνητικού προγράμματος αφορούν τα δημογραφικά σας στοιχεία (όνομα και επίθετο, ημερομηνία γέννησης, φύλο, εθνικότητα, μορφωτικό επίπεδο, επάγγελμα, οικογενειακή κατάσταση, τόπος διαμονής), στοιχεία επικοινωνίας (τηλέφωνο) και τις απόψεις σας όσον αφορά το θέμα της έρευνας.

Η ερευνήτρια (Ελένη Δημητρίου) και μόνο αυτή θα έχει πρόσβαση στα προαναφερόμενα στοιχεία και σε όλες τις πληροφορίες που θα παρέχετε στην πρωτότυπη μορφή τους (ηχογραφημένο υλικό) κατά τη διάρκεια της συνέντευξης και των ομάδων συζήτησης. **Κανένας άλλος δε θα έχει πρόσβαση στα δημογραφικά σας στοιχεία και τις πληροφορίες που θα παρέχετε**. Με την ολοκλήρωση των συνεντεύξεων και των ομάδων συζήτησης, θα πραγματοποιηθεί απομαγνητοφώνηση των συνεντεύξεων και των ομάδων συζήτησης, όπου θα εφαρμοστούν από την ερευνήτρια τα απαιτούμενα πρωτόκολλα ανωνυμίας, θα δοθούν δηλαδή ψευδώνυμα σε κάθε συμμετέχοντα και θα αφαιρεθούν πληροφορίες που μπορεί να μαρτυρούν την ταυτότητα κάποιου συμμετέχοντα, όπως ονόματα, ημερομηνίες, τοποθεσίες, κτλ. Εφόσον ολοκληρωθεί η διαδικασία ανωνυμίας, η υπεύθυνη του ερευνητική προγράμματος (Δρ Ειρήνη Καδιανάκη) θα έχει πρόσβαση στα ανώνυμα αντίγραφα των συνεντεύξεων και των ομάδων συζήτησης. Ανώνυμα αποσπάσματα από τη συνέντευξη ή την ομάδα συζήτησης ενδεχομένως συμπεριληφθούν στη διδακτορική διατριβή της ερευνήτριας ή/και σε μελλοντικές δημοσιεύσεις σε ερευνητικά περιοδικά. Όλες οι παραπάνω πληροφορίες θα φυλαχθούν για χρονικό διάστημα πέντε ετών και στη συνέχεια θα καταστραφούν (βλέπε «περιγραφή διαδικασιών χειρισμού δεδομένων ή/και βιολογικών δειγμάτων συμμετεχόντων που θα (συνεχίζεται) αποσυρθούν από τη μελέτη πριν την ολοκλήρωση της»).

Επίθετο:		Όνομα:	
Υπογραφή:		Ημερομηνία	

ΟΠΟΥ ΙΣΧΥΕΙ, ΜΕΛΛΟΝΤΙΚΗ ΑΠΟΘΗΚΕΥΣΗ ΚΑΙ ΧΡΗΣΗ ΒΙΟΛΟΓΙΚΩΝ ΔΕΙΓΜΑΤΩΝ ΚΑΙ ΠΡΟΣΩΠΙΚΩΝ ΔΕΔΟΜΕΝΩΝ:

Παρακαλούμε σημειώστε και υπογράψτε είτε αριστερά είτε δεξιά

Εκτός από τους σκοπούς του παρόντος προγράμματος που θα διαρκέσει …….. χρόνια **Αποδέχομαι** ☐ όπως: Υπογραφή:	Εκτός από τους σκοπούς της παρούσας μελέτης που θα διαρκέσει …….. χρόνια **Δεν αποδέχομαι** ☐ όπως: Υπογραφή:

τα βιολογικά μου δείγματα (παρειακά επιχρίσματα ή σάλιο ή DNA) και γενετικά δεδομένα μου που θα φυλάσσονται στο ……………………………………………………………………………………………… **<u>να μπορούν να κρατηθούν πέραν των ………. χρόνων και να χρησιμοποιηθούν σε μελλοντικές μελέτες</u>** αφού πρώτα εγκριθεί κάτι τέτοιο από την Εθνική Επιτροπή Βιοηθικής Κύπρου (ΕΕΒΚ) μετά από σχετικό αίτημα ανανέωσης προς την ΕΕΒΚ από τον υπεύθυνο ερευνητή του παρόντος προγράμματος. Καταλαβαίνω ότι θέματα εμπιστευτικότητας θα ισχύουν πάντοτε.

Σε περίπτωση που ανακαλυφθούν νέες πληροφορίες που επηρεάζουν άμεσα την υγεία σας θα θέλατε να πληροφορηθείτε;

ΝΑΙ ☐	ΟΧΙ ☐	ΔΕΝ ΜΠΟΡΩ ΝΑ ΑΠΟΦΑΣΙΣΩ ΤΩΡΑ, ΝΑ ΕΡΩΤΗΘΩ ΕΚ ΝΕΟΥ ΕΦΟΣΟΝ ΥΠΑΡΞΕΙ ΑΝΑΓΚΗ ☐

Λεπτομέρειες για το ποια δεδομένα θα προκύψουν για σας στα πλαίσια του προγράμματος και ποιος/ποιοι θα έχουν πρόσβαση σε αυτά και για πόσο χρονικό διάστημα.

Τα δεδομένα που θα προκύψουν στα πλαίσια του ερευνητικού προγράμματος αφορούν την εμπειρία της αναπηρίας του παιδιού σας και τις απόψεις σας επί του θέματος, όπως εσείς την κατανοείτε. **Μπορείτε να μοιραστείτε όσες πληροφορίες νιώθετε άνετα να συζητήσετε** και να περιγράψετε την εμπειρία σας με τον τρόπο που εσείς επιλέξετε. Σε αυτές τις πληροφορίες, στην πρωτότυπη μορφή τους (δηλαδή ηχογραφημένες συνεντεύξεις και ομάδες συζήτησης) θα έχει πρόσβαση μόνο η ερευνήτρια (Ελένη Δημητρίου) και κανένας άλλος. Με την ολοκλήρωση των συνεντεύξεων και των ομάδων συζήτησης, θα πραγματοποιηθεί απομαγνητοφώνηση των συνεντεύξεων και των ομάδων συζήτησης, όπου θα εφαρμοστούν από την ερευνήτρια τα απαιτούμενα πρωτόκολλα ανωνυμίας, θα δοθούν δηλαδή ψευδώνυμα σε κάθε συμμετέχοντα και θα αφαιρεθούν πληροφορίες που μπορεί να μαρτυρούν την ταυτότητα κάποιου συμμετέχοντα, όπως ονόματα, ημερομηνίες, τοποθεσίες, κτλ. Εφόσον ολοκληρωθεί η διαδικασία ανωνυμίας, η υπεύθυνη του ερευνητική προγράμματος (Δρ Ειρήνη Καδιανάκη) θα έχει πρόσβαση στα ανώνυμα αντίγραφα των συνεντεύξεων και των ομάδων συζήτησης. Ανώνυμα αποσπάσματα από τη συνέντευξη ή την ομάδα συζήτησης ενδεχομένως συμπεριληφθούν στη διδακτορική διατριβή της ερευνήτριας ή/και σε μελλοντικές δημοσιεύσεις σε ερευνητικά περιοδικά. Όλες οι παραπάνω πληροφορίες θα φυλαχθούν για χρονικό διάστημα **πέντε ετών** και στη συνέχεια θα καταστραφούν (βλέπε «περιγραφή διαδικασιών χειρισμού δεδομένων ή/και βιολογικών δειγμάτων συμμετεχόντων που θα αποσυρθούν από τη μελέτη πριν την ολοκλήρωση της»).

Επίθετο:		Όνομα:	
Υπογραφή:		Ημερομηνία:	

Αναμενόμενο όφελος για τους συμμετέχοντες

Οι συμμετέχοντες αναμένεται να επωφεληθείτε από αυτή την έρευνα καθώς θα έχετε την ευκαιρία να συζητήσετε την εμπειρία της αναπηρίας του παιδιού σας και πως αυτή η εμπειρία σας επηρεάζει σε ένα ασφαλές περιβάλλον, κάτι το οποίο ενδεχομένως βοηθήσει στην ευρύτερη κατανόηση σας και επεξεργασία αυτής της εμπειρίας. Πιο συγκεκριμένα, η συμμετοχή σας στις ατομικές συνεντεύξεις θα σας δώσει την ευκαιρία να προβληματιστείτε σχετικά με την εμπειρία της αναπηρίας του παιδιού σας και, ενδεχομένως, να (συνεχίζεται) διευρύνετε την αντίληψή σας επί του θέματος. Η ομάδα συζήτησης θα σας δώσει την ευκαιρία να αλληλεπιδράσετε με άλλους γονείς που βρίσκονται σε παρόμοια θέση, να έρθετε αντιμέτωποι με διαφορετικές απόψεις επί του θέματος και να ανταλλάξετε απόψεις σχετικά με ένα κοινό θέμα που αντιμετωπίζετε καθημερινά. Τόσο η συνέντευξη όσο και η ομάδα συζήτησης μπορεί να αποτελέσουν το σημείο εκκίνησης για περαιτέρω επεξεργασία αυτής της εμπειρίας, την αρχή δηλαδή μιας διαδικασίας προσωπικής σας ανάπτυξης.

Επιπλέον, μέσα από τη συμμετοχής σας στην έρευνα αυτή θα συμβάλλετε στην ανάπτυξη της ακαδημαϊκής γνώσης όσον αφορά την κατανόησης της εμπειρίας της αναπηρίας του παιδιού από τους γονείς. Η γνώση αυτή θα μπορούσε να αξιοποιηθεί για να δημιουργηθούν κατάλληλα προγράμματα στήριξης των γονιών αλλά και προγράμματα ευαισθητοποίησης σχετικά με θέματα αναπηρίας.

Αναμενόμενο όφελος για ερευνητές ή/και χρηματοδότες

Το όφελος για την ερευνήτρια εντοπίζεται στην λεπτομερή εξέταση και κατανόηση του θέματος της εμπειρίας των γονιών που μεγαλώνουν παιδί με νοητική αναπηρία ή αυτισμό, πως βιώνουν αυτή την εμπειρία, πως την ερμηνεύουν και πως τους επηρεάζει. Τα στοιχεία αυτά αποτελούν βασικά ερωτήματα της διδακτορικής διατριβής της ερευνήτριας ενώ μπορεί να αποτελέσουν το θέμα μελλοντικών δημοσιεύσεών της σε ερευνητικά περιοδικά ή παρουσιάσεων σε ερευνητικά συνέδρια.

Λεπτομέρειες συνθηκών τερματισμού ή πρόωρης διακοπής του ερευνητικού προγράμματος.

Οποιαδήποτε στιγμή έχετε το δικαίωμα να αποχωρήσετε από το ερευνητικό πρόγραμμα και να αποσύρετε τη συγκατάθεσή σας. Σε αυτή την περίπτωση, δε χρειάζεται να εξηγήσετε το λόγο ούτε υπάρχει κάποια συνέπεια για αυτή σας την απόφαση.

Σε περίπτωση που επιθυμείτε να αποχωρήσετε από το ερευνητικό πρόγραμμα, θα πρέπει να επικοινωνήσετε με την ερευνήτρια ή την επιστημονική υπεύθυνη του προγράμματος στα παρακάτω στοιχεία επικοινωνίας:

Ελένη Δημητρίου – Ερευνήτρια
Διδακτορική Φοιτήτρια, Πρόγραμμα Κλινικής Ψυχολογίας, Πανεπιστήμιο Κύπρου
Email: dimitrioueleni@gmail.com, Τηλ.: 96755529

Δρ. Ειρήνη Καδιανάκη – Επιστημονική Υπεύθυνη
Επίκουρη Καθηγήτρια, Τμήμα Ψυχολογίας, Πανεπιστήμιο Κύπρου
Email: kadianaki.irini@ucy.ac.cy, Τηλ.: 22892063

Χώρος και χρονική διάρκεια φύλαξης δεδομένων ή/και βιολογικών δειγμάτων που θα ληφθούν στο πλαίσιο του προγράμματος

Όλες οι πληροφορίες που θα συγκεντρωθούν κατά τη διάρκεια αυτού του ερευνητικού προγράμματος, θα φυλαχθούν στο Τμήμα Ψυχολογίας του Πανεπιστημίου Κύπρου για διάστημα **πέντε ετών**. Οι πληροφορίες αυτές αφορούν τα συμπληρωμένα αντίγραφα των εντύπων συγκατάθεσης, το ηχογραφημένο υλικό από τις συνεντεύξεις και τις ομάδες συζήτησης. Τα δεδομένα που θα είναι σε έντυπη μορφή θα φυλαχθούν σε θυρίδα ασφαλείας, σε κλειδωμένο ντουλάπι στο Τμήμα Ψυχολογίας του Πανεπιστημίου Κύπρου. Τα δεδομένα που θα είναι σε ηλεκτρονική μορφή (δηλαδή ηχογραφημένες συνεντεύξεις και ομάδες συζήτησης, ανώνυμα αντίγραφα απομαγνητοφωνήσεων συνεντεύξεων και ομάδων συζήτησης) θα προστατεύονται από κωδικό ασφαλείας σε υπολογιστή που θα βρίσκεται στο Τμήμα Ψυχολογίας του Πανεπιστημίου Κύπρου. Το μοναδικό άτομο που θα έχει πρόσβαση στα κλειδιά της θυρίδας ασφαλείας και θα γνωρίζει τον κωδικό ασφαλείας του υπολογιστή που προαναφέρθηκαν θα είναι η ερευνήτρια (Ελένη Δημητρίου). Η επιστημονική υπεύθυνη του ερευνητικού προγράμματος (Δρ. Ειρήνη Καδιανάκη) θα έχει πρόσβαση μόνο στα ανώνυμα αντίγραφα απομαγνητοφωνήσεων συνεντεύξεων και ομάδων συζήτησης.

Επίθετο:		Όνομα:	
Υπογραφή:		Ημερομηνία:	

Περιγραφή διαδικασιών χειρισμού δεδομένων ή/και βιολογικών δειγμάτων συμμετεχόντων που θα αποσυρθούν από τη μελέτη πριν την ολοκλήρωση της.

Αφού συμπληρωθούν πέντε χρόνια από την ημερομηνίας συλλογής των δεδομένων των συνεντεύξεων και των ομάδων συζήτησης, τα δεδομένα θα καταστρέφονται. Επιπλέον, τα δεδομένα θα καταστρέφονται αμέσως σε περίπτωση συμμετεχόντων που επιθυμούν να αποσύρουν τη συγκατάθεσή τους. Η καταστροφή των δεδομένων θα περιλαμβάνει διαγραφή από τον ηλεκτρονική υπολογιστή (διαγραφή από τα αρχεία και από τον κάδο ανακύκλωσης του Η/Υ) και καταστροφή των έντυπων αρχείων μέσω μηχανής τεμαχισμού. Η διαδικασία καταστροφής των δεδομένων θα γίνει αποκλειστικά από την ερευνήτρια (Ελένη Δημητρίου).

Πλήρη στοιχεία επικοινωνίας και θέση ατόμου στο οποίο οι συμμετέχοντες μπορούν να υποβάλλουν παράπονα ή καταγγελίες που αφορούν το πρόγραμμα στο οποίο συμμετέχουν.

Για οποιοδήποτε παράπονο ή καταγγελία σχετικά με τη διεξαγωγή και το περιεχόμενο του συγκεκριμένου ερευνητικού προγράμματος μπορείτε να αποταθείτε στον Προϊστάμενο της Υπηρεσίας Υποστήριξης Έρευνας του Πανεπιστημίου Κύπρου:

Δρ. Μάριος Δημητριάδης
Υπηρεσία Υποστήριξης Έρευνας Πανεπιστημίου Κύπρου
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Πλήρη στοιχεία επικοινωνίας και θέση ατόμου στο οποίο οι συμμετέχοντες μπορούν να απευθυνθούν για περισσότερες πληροφορίες ή διευκρινήσεις για το ερευνητικό πρόγραμμα.

Ελένη Δημητρίου – Ερευνήτρια
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Επίθετο:		Όνομα:	
Υπογραφή:		Ημερομηνία:	

Appendix C: List of support services for participants

ΣΥΜΒΟΥΛΕΥΤΙΚΕΣ ΥΠΗΡΕΣΙΕΣ

Τοπική αυτοδιοίκηση

Συμβουλευτικό Κέντρο Πολυδύναμου Δημοτικού Κέντρου Λευκωσίας. Τηλ. 22797868 / 870

Συμβουλευτικό Κέντρο Πολυδύναμου Δημοτικού Κέντρου Στροβόλου (συνεργασία με το Πανεπιστήμιο Λευκωσίας και το Συστημικό Ινστιτούτο Κύπρου)
Τηλ. 22511728, 22311534

Συμβουλευτικό Κέντρο Αγλαντζιάς (συνεργασία με το Κέντρο Ψυχικής Υγείας Πανεπιστημίου Κύπρου). Τηλ. 22892136

Κέντρο Παροχής Κοινωνικών Υπηρεσιών Πολυδύναμου Κέντρου Αγίου Δομετίου
Τηλ. 22392018

Συμβουλευτικό Κέντρο Αραδίππου (συνεργασία με το Πανεπιστήμιο Λευκωσίας)
Τηλ. 24811081, 24811083, 24813010

Κέντρο Στήριξης για την Οικογένεια και τους Νέους «Ηράκλειτος» Κ. Πολεμιδιών
Τηλ. 25771271, 25397277, email: irakleitos@cytanet.com.cy

Συμβουλευτικό Κέντρο Οικογένειας & Παιδιού «Ίρις» Γεροσκήπου. Τηλ. 99233222

Άλλοι φορείς

Κέντρο Έρευνας και Συμβουλευτικών Υπηρεσιών Πανεπιστημίου Λευκωσίας (ΚΕΣΥ)
Τηλ. 22795100, email: kesy@unic.ac.cy

Συμβουλευτικές Υπηρεσίες «Πρόταση» Οργανισμού Νεολαίας Κύπρου (Παγκύπρια κάλυψη)
Τηλ. 97725204

Σταθμός Πρόληψης και Συμβουλευτικής «Ιθάκη» Πέρα χωριό Νήσου. Τηλ. 22524826

Appendix D: Interview Topic Guide

Demographic, social and other data

- Age
- Place of residence
- Occupation
- Educational level
- Marital status (including previous marriages or other children, if any)
- Who is the primary caregiver of the child?
- Presence of a support network
- Presence or absence of another person with a disability in the immediate or extended environment
- Activism action

Representation of disability

- ✓ What is the first thing that comes to your mind when you hear the word 'disability'?
- ✓ What emotions do you feel when you hear about disability?
- ✓ Can you describe the first experience related to disability that you ever had in your life? How did that experience make you feel?
  Can you say a few words about this experience? (In case you are not referring to your own child's experience)
- ✓ What is your stance towards people with (participant's term)?
- ✓ When referring to people with disabilities, some people very often say "poor thing". What is your opinion of this? How does that reaction make you feel?
- ✓ What is your opinion on various public events for people with disabilities, such as bazaars, 'radiomarathon', etc?

Definition of intellectual/developmental disability

- ✓ How do you refer to someone with a similar syndrome/disorder to that of your child?
- ✓ Do you know of any other terms?
- ✓ How do the people around you refer to them?
- ✓ In the past, the term 'mental retardation' was used to describe people who face similar issues. Nowadays, other terminologies have prevailed. What is your opinion of this?
- ✓ In your opinion, what is the main difference between disability and (participant's term)?

Secondary stigma & social context

- ✓ How do you think the world views people with (participant's term)?
- ✓ How does the world believe the lives of people with (participant's term) are?
- ✓ What do you think the world feels towards people with (participant's term)?

- ✓ How do you think the world views you as the father/mother of (child’s name)?
- ✓ How did your family and friends react when they learned that (child’s name) has (name of the syndrome/disorder)?
  How do you think they view you?
  How did that make you feel?
  How did you react?
- ✓ Have you ever discussed (name of the syndrome/disorder) of (child's name) with others? Did you initiate this discussion?
  What exactly did you discuss?
  What did the others say? Who were they?

Reception of disability

- ✓ How did you learn about (child’s name) (name of the syndrome/disorder)? What was your initial reaction to this disclosure?
- ✓ What did you understand when the doctor/other professional mentioned the (name of the syndrome/disorder)? How did you feel?
- ✓ What or whom do you remember more vividly from those days of the diagnosis?
- ✓ How did you react on the days following the diagnosis? (Isolation? Second opinion? Stress-relieving actions?)
- ✓ How did your close environment react?
- ✓ Did their reaction help you?
- ✓ How did that disclosure affect your family life/daily life of the family?
- ✓ When did your family return to their routine/daily life?
- ✓ What happened in the meantime?

Meaning & interpretation of disability

- ✓ Initially, how do you remember yourself perceiving this issue?
- ✓ How do you perceive it now?
- ✓ If I asked you to describe your child’s (name of the syndrome/disorder) in 3 words, what would those be?
- ✓ After the diagnosis, did you notice if you started participating in any activities/hobbies that you didn’t used to do before? If yes, what are they?
- ✓ How do you feel when you participate in (…)?
- ✓ Are there any activities that offer you relief from your feelings?
- ✓ Can you provide me with an example?
- ✓ Have you tried to give an interpretation, some explanation?
- ✓ Is there something (anything) that has helped you in this interpretation, like habits, actions, activities, occupations?
- ✓ Have you read anything that has influenced the way you view the issue?
- ✓ Have you heard anything related to this topic in mass media or social media (radio, TV, Internet, Facebook)? How did you feel?

- ✓ Have you read any relevant publication or book that was particularly meaningful to you? Why?
- ✓ Have you listened to any relevant music (or other form of art) that was particularly meaningful to you? Why?
- ✓ Have you watched a relevant film or series that was particularly meaningful to you? Why?
- ✓ Has there been any particular stimulus that has significantly influenced the way you perceive the issue? How has it affected you?
- ✓ Has there been any action (some belief/beliefs) that was particularly meaningful to you, that stands out to you? Why is it special to you?

Acceptance or rejection of the diagnosis

- ✓ Do you think you have accepted it?
  (YES) What helped you accept (child's name) (name of the syndrome/disorder)?
  (NO) What do you think would help you accept (child's name) (name of the syndrome/disorder)?
- ✓ Are there any values or institutions that have influenced the way you perceive the issue of disability? In what way?
- ✓ As a parent of a child with (name of the syndrome/disorder), do you have a lot of responsibilities? Where do you draw strength/energy from to cope?
- ✓ With the experiences you've had so far, what meaning do you attribute to disability?
- ✓ What does your child's disability mean to you?
- ✓ What have you gained from the entire experience of (child's name) (name of the syndrome/disorder)?
- ✓ Is there any positive in the entire experience of (child's name) (name of the syndrome/disorder)?
- ✓ Do you have friends who have a child with (name of the syndrome/disorder)? Do you find talking to them helpful?
- ✓ What would you say to someone close to you who has found out that his kid has similar (participant's term)?

End of the interview

- ✓ Everything you have told me is valuable for the research I am conducting. I don't think I need to ask you anything else. Is there anything else you would like to add?
- ✓ How did you feel during this interview?
- ✓ What do you think made you feel this way?
- ✓ How do you feel now that the interview is over?
- ✓ Given your experience in this interview, would you agree to participate in another interview on this subject?

CwD: Child with a Disability
PwD: Person with a Disability

Appendix E: Focus Group Topic Guide

Introduction

- Short self-representation of each participant
- Optional reporting on the child’s diagnosis and/or the type of disability

Representation of disability

- ✓ What do you think when you hear the word ‘disability’?
- ✓ Reading of relevant anonymous excerpt from an interview and open discussion.

Definition of intellectual/developmental disability

- ✓ Let’s assume that we have a group of 4 people: One with Down syndrome, the other with autism, the other with cerebral palsy and the other with a neuro-developmental disorder. If we wanted to describe them as a group, how would we call that group?
- ✓ How do the people around you call them?

Reception of disability

- ✓ How did you learn about your child’s syndrome or disability?
- ✓ What did you understand when the doctor/other professional mentioned the syndrome or disorder?
- ✓ What do you think about your child’s syndrome or disorder now?
- ✓ Reading of relevant anonymous excerpt from an interview and open discussion.

Meaning & interpretation of disability

- ✓ Have you tried to give an interpretation to your child’s disability/disorder/diagnosis? Have you arrived at an explanation?
- ✓ Is there something (anything) that has helped you in that interpretation?
- ✓ Have you read or heard anything that has influenced the way you view the issue?
- ✓ Are there any values or institutions that have influenced the way you perceive the issue of disability/disorder/diagnosis? In what way?
- ✓ Reading of relevant anonymous excerpt from an interview and open discussion.

Ending of focus group session

- ✓ Would anyone like to add something?
- ✓ Short comment by every participant about how they felt during this discussion.

Appendix F: Coding List

1. Relationships of the immediate family members of the child with a disability or autism.
Report on the relationships and interactions among the immediate family of the child with autism or a disability.

2. Relationships of extended family members, friends, and third parties with the child with a disability or autism and with the parent.
Report on the relationships and interactions within the extended family members, friends, and third parties with the child with a disability or autism and with the parent

3. Pregnancy, labor and family planning.
Report on matters regarding the pregnancy, the childbirth and the perinatal period of the mother. Parent's perspective regarding matters of childbirth, prenatal screening, relevant decisions, and family planning.

4. Report on the interview, previous conversations or the parents' focus group.
Parent's report on the specific interview, on previous conversations with the researcher or on the discussions during the parents' focus group. Questions and addressing the researcher.

5. The parent's values and beliefs.
Report on values, beliefs or actions/activities that have influenced the way that the parent views the fact of raising a child with a disability or autism. Report on the how these values, beliefs or actions/activities influence the parent.

6. Evaluation, therapeutic intervention and education of individuals with autism or disabilities. Involved professionals.
Report on the evaluation, the therapeutic process and the content of therapies or interventions related to the child(ren) or individuals with a disability or autism. Report on the professionals who are involved in the evaluation, diagnosis, support, education or the therapy of individuals with a disability or autism.

7. The parent's coping mechanisms.
Report on the ways, the elements and factors that provide strength and/or help or would help the parent cope with the daily life and the needs of the child with autism or a disability.

8. Acceptance of child's diagnosis by each parent. The parent’s relationship with diagnosis.

Report on the acceptance, the recognition, and/or the realization of the child’s diagnosis by themselves or the other parent. The parent’s relationship with the diagnosis in the past and in the present. Factors or/and elements that helped or would have helped each parent to accept, recognize or/and realize their child’s diagnosis.

9. The parent’s assistance/support network.

Report on the support network and on the ways of supporting the parent and his/her family. Report on the lack of a supportive assistance network. It does not concern help/support from professionals. Report on the parent’s needs for assistance and support.

10. The parent’s participation or actions due to their child’s diagnosis.

Report on activities, groups, associations, centers, or other activities that the parent is aware of or participates in due to the child's diagnosis. Report on the consequences of the parent's involvement in these activities.

11. The parent's relevant experiences to disabilities or autism, besides those of their own child.

Report on the parent’s experiences and involvement with disability or diversity-related issues in the past, present or future, besides those of their own child. Report on how these experiences have influenced or currently influence the parent.

12. Inclusion or exclusion of individuals with autism or a disability.

Report on incidents, actions, behaviors aimed at or facilitating the inclusion or/and integration of individuals with autism or a disability. Report on incidents, actions, behaviors that lead to the exclusion or segregation of individuals with autism or a disability. The parent's reaction to the inclusion or exclusion of individuals with autism or a disability.

13. Disclosing (or not disclosing) the diagnosis to extended family or friends/third parties. The reaction of the extended family, friends or/and third parties to the diagnosis or/and the disclosure of the diagnosis.

Report on the way the parents chose to disclose (or not disclose) their child’s diagnosis or/and their experience to the extended family, friends or third parties. Report on the decision to disclose or not disclose the diagnosis. Report on the reaction of the extended family, friends or third parties to the disclosure of the child’s diagnosis with autism or a disability. Report on how the parent experienced these reactions. Report on discussions regarding the child’s diagnosis or/and their experience as the parents of a child with autism or a disability.

14. The stimuli and information the parent received regarding autism or their child’s diagnosis.

Report to any kind of stimuli experienced by the parent regarding autism, the diagnosis or their child’s disability. Information the parent received, research, and study the parent undertook regarding autism, another diagnosis or/and disability. Report on how this information has influenced or currently influences the parent.

15. The diagnosis disclosure and the reaction of the parent and the immediate family to the diagnosis disclosure.

Report on the diagnosis disclosure by the professionals involved. The parent’s reaction (emotions, thoughts or behaviors) to the diagnosis disclosure. Report on what each parent understood from the diagnosis disclosure and how they experienced it. Report on the parent's needs (emotional or/and practical) during the diagnosis disclosure. The reaction of the other parent (emotions, thoughts or behaviors) and the rest of the members of the immediate family to the diagnosis disclosure. Report on the professionals’ approach to the diagnosis disclosure and to the reaction of the parent regarding the professionals’ approach.

16. The parent’s experience of raising a child with a disability.

Emotions, thoughts and actions experienced or being experienced as a parent of child with a disability. Report on the positive or/and negative aspects identified from the experience of raising a child with a disability. Report on the importance of this experience for the parent.

17. The parent’s experience of raising a child with autism.

Emotions, thoughts and actions experienced or being experienced as a parent of child with autism. Report on the positive or/and negative aspects identified from the experience of raising a child with autism. Report on the importance of this experience for the parent.

18. The interpretation and the meaning for the parent regarding autism, disability, or their child's diagnosis.

Report on the parent’s interpretation of their child having autism or a disability. Report on the meaning the parent assigns to their child having autism or a disability. Report on how the parent is affected by the interpretation and the meaning they assign to it. General questions and thoughts the parent has regarding their child’s diagnosis.

19. The road to diagnosis.

Report on the investigation period and the process of diagnosing their child. Incidents, behaviors, indications, or other factors involving the parent or/and the immediate family that occurred during the investigation period or the diagnosis. Report on the parent’s reaction (emotions, thoughts, or behaviors) to the early signs of the disorder before the official diagnosis. This does not concern the actual diagnosis disclosure itself.

20. The parent’s effort to improve their child’s condition. Parental methods and practices.

Report on the parent’s effort or the lack thereof to improve their child’s condition. Methods, practices, approaches, or strategies that the parent employs to raise their child.

21. The relationship of the parent and the child with autism or disability.

Report on the relationship and interaction between the parent and the child with autism or a disability.

22. The parent's relationship with religion and faith.

Report on actions, behaviors or expressions that are directly or indirectly related to religion. Report on institutions, organizations, and individuals that are professionally engaged in religion and faith. The parent's relationship with religion and faith. The role of religion and faith in the way that the parent perceives and copes with the issue of their child's diagnosis.

23. Mother and maternal role. Father and paternal role. Parenting.

Report on the roles of the mother and the father. Report on how the maternal role affects a woman and how the paternal role influences a man. The capabilities and needs of a mother and a father. Report on the similarities and differences of the two roles. The consequences of parenting to a mother or/and a father.

24. Bazaars, fund raisers and charity events.

Report on bazaars, fund raisers, and charity events for individuals with a disability or autism. Report on the parent’s opinion for these charity events.

25. Disability, diversity, and individuals with a disability in general.

Report on disability, diversity, and individuals with a disability or/and diversity in general. This does not pertain to the interviewees’ children.

26. Children and individuals without autism or a disability. Comparison between children/individuals with and without autism or a disability.

Report on children/individuals without autism, a disability, or any other forms of diversity. Report on the comparisons between the child with autism or a disability to other children with autism or a disability, or to children without autism or a disability. Report on the normal and abnormal.

27. Autism, the autism spectrum, and individuals with autism in general.

Report on autism, the autism spectrum, and individuals with autism in general. This does not pertain to the interviewees' children.

28. The disability or the diagnosis (aside from autism) of the interviewee's child. Child's description in general.

Report on the disability or the diagnosis of the child and on the child as an individual with a disability or an individual with a different diagnosis. General description of the interviewee's child.

29. Autism in the interviewee's child. Child's description in general.

Report on the child's autism and on the child as an individual with autism. General description of the interviewee's child.

30. Policy, institutions or procedures related to individuals with a disability or autism.

Report on policies, legislation, institutions, or other processes within government departments/agencies/sections related to individuals with a disability or autism. Report on requests, opinions and the parent's relationship with policies, institutions, and existing procedures. Report on adjustments, accommodations, and other forms of assistance for individuals with a disability or autism. Description of actions taken to inform or raise awareness of the general public regarding autism or disability.

31. The parent's approach in matters of disability or autism and towards individuals with a disability or autism.

Report on the parent's approach (opinions, behaviors) regarding disability or autism issues towards individuals with a disability or autism and towards those individuals' parents. Report on the factors that influence or determine the approach towards disability or autism or the approach towards individuals with disability that the parent chooses. This does not pertain to the interviewees' children.

32. Others' approach towards the parents of individuals with autism or/and a disability.

Report on others' approach (opinions, behaviours) towards the parents of individuals with autism or/and a disability. The parent's response to this approach.

33. Other’s approach in matters of disability or autism and towards individuals with a disability or autism.

Report on other’s approach (opinions, behaviours) regarding disability or autism issues, and other's approach towards individuals with a disability or autism. The parent’s response to this approach.

34. Background information and demographic data.

Report on demographic information (age, place of residence, marital status, education, occupation etc) and on background information (individual, family) of the parents and the family.

35. Relationship with other parents of kid(s) with autism or a disability, or with parents of kids with typical development.

Report on the relationship and interaction with parents of kid(s) with autism or a disability, or with parents of kids with typical development.

36. Ceremonies, rites and rituals related to autism, disability, or the child itself.

Description of ceremonies, rites, rituals related (directly or indirectly) to autism, disability or to the child itself. Including religious or/and other rites.

Report on how these rites influence the parent.

37. Changes or non-changes after the diagnosis. Phases in experiencing the child’s disability or autism.

Report on what changed or what hasn’t changed after the diagnosis of the child with autism or a disability (short-term or long-term changes). Report on how these changes influenced the parent and on how the parent changed through experiencing their child’s autism or disability. Report on the parent's needs (emotional or/and practical) after the diagnosis. Report on the phases that the parent recognizes in experiencing (themselves or the other parent) their child’s autism, or the diagnosis of their child.

38. The future and the progress of the child with autism or a disability and its’ family.

Report on the future of the child with autism or a disability, the future of the parent and the family. Report on the parent’s expectations, goals and hopes for the future and the progress of the child with autism or a disability. Report on possible hypothetical or future scenarios.

39. Humour, sarcasm and witticisms.

Expressions or words that contain humour, sarcasm or/and witticisms about their child, the child's diagnosis or for the parent themselves.

Appendix G: Coding List – Clusters of codes

Cluster 1: Description of autism and disability. Comparison between children without autism or a disability.

Cluster 2: Others’ approach in matters regarding autism or disability. Approach towards parents of children with autism or a disability.

Cluster 3: Relationships among the immediate and extended family. Relationships with other parents.

Cluster 4: The broader experience of the parents with a child of autism or/and disability.

Cluster 5: Parental expectations, effort and progress of the child with autism or a disability.

Cluster 6: Information or stimuli regarding matters of autism or/and disability. Participation in actions and wider engagement of the parents in matters regarding autism or/and disability.

Cluster 7: Religion, values, rituals related to the child’s diagnosis and the parents’ experience.

Cluster 8: The road to diagnosis. The diagnosis disclosure. The reactions to the diagnosis disclosure from the parents, the extended family or/and third parties.

Cluster 9: Policy (governmental or private), institutions and charity organizations.

Cluster 10: Pregnancy, family planning and parenting.

Appendix H: Table 1. Participants' demographic characteristics (parents and children)

	Parent's name	Parent's age	Marital status	Native Cypriot	Child's name	Child's age	Child's diagnosis	Siblings	Individual interview / focus group	Wife / husband's participation
1.	Georgia [43]	34	Married	Yes	Andreas [44]	5	Autistic Spectrum Disorder	Yes	Individual	No
2.	Ioanna	33	Married	Yes	Anastasios	7 ½	Intellectual disability, cerebral palsy	No	Individual	No
3.	Christina	38	Married	No	Antonis	7 ½	Autistic Spectrum Disorder	Yes	Individual	Yes
4.	Angela	46	Married	Yes	Christophoros	7	Autistic Spectrum Disorder	Yes	Individual	No
5.	Xenia	48	Married	Yes	Panayiotis	7 ½	Autistic Spectrum Disorder	No	Individual	Yes
6.	Marina	38	Married	Yes	Maria	9	Psychomotor delay, epilepsy, autistic traits	Yes	Both	No
7.	Maria	47	Married	Yes	Christos	6	Down syndrome	Yes	Both	Yes
8.	Antonia	36	Married	Yes	Philippos	6	Mild global developmental delay, autistic traits	Yes	Individual	Yes

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[43] All parents' names are pseudonyms.
[44] All children's names are pseudonyms.

9.	Loucas	53	Married	Yes	Panayiotis	7 ½	Autistic Spectrum Disorder	No	Individual	Yes
10.	Alexandros	42	Married	No	Philippos	6	Mild global developmental delay, autistic traits	Yes	Individual	Yes
11.	Marios	48	Married	Yes	Christos	6	Down syndrome	Yes	Individual	Yes
12.	Katerina	40	Single	No	Costas	11 ½	Alpha syndrome [45]	Yes	Individual	No
13.	Evangelia	39	Married	Yes	Aris	6	Autistic traits	Yes	Both	No
14.	Eleftheria	51	Married	Yes	Sophia	11	Autistic Spectrum Disorder	Yes	Individual	Yes
15.	Irene	45	Married	No	Nayia	11	Cerebral palsy, autistic traits	Yes	Both	No
16.	Andriana	46	Married	Yes	Petros	8	Down syndrome, autistic traits	Yes	Individual	No
17.	Nicolas	40	Married	Yes	Natalie	5	Global psychomotor delay, congenital brain disorder	Yes	Individual	No
18.	Demetra	44	Divorced	Yes	Natasha	6	Alpha syndrome [44]	No	Individual	No
19.	Marcos	43	Married	No	Antonis	7 ½	Autistic Spectrum Disorder	Yes	Individual	Yes
20.	Demetris	58	Married	Yes	Sophia	11	Autistic Spectrum Disorder	Yes	Individual	Yes
21.	Yiannis	40	Married	No	Alexandra	4	Nodular sclerosis, epilepsy, speech delay	Yes	Individual	No

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[45] Alpha syndrome is a pseudonym of a rare syndrome.

22.	Elena	49	Married	Yes	Stephanos	10 ½	Autistic Spectrum Disorder	Yes	Individual	No
23.	Vasilis	48	Married	Yes	Anna	6 ½	Pervasive developmental disorder, speech disorder, global developmental delay	Yes	Individual	No
24.	Theodora	51	Married	Yes	Petros	5	Autistic Spectrum Disorder	Yes	Individual	No
25.	Anastasia	38	Divorced	Yes	Grigoris	7 ½	Autistic Spectrum Disorder	No	Focus group	No
26.	Athina	36	Divorced	Yes	Angelos	4	Autistic Spectrum Disorder	Yes	Focus group	No