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The Well-being and Difficulties for Siblings of Disabled Children during the Developmental Age

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INTRODUCTION

"Families with disabilities are diverse; economic hardship disproportionately characterizes their lives; family life with disabilities is a journey that includes stress and resilience, with support contributing significantly to the latter; and that work benefits and taxes family life." (Farrell & Krahn, 2014, p.1)

Although research of the last decade has developed an initial understanding on the experience of siblings of disabled children, it is still a new area of research that does not lack controversies and inconsistencies within the literature, especially regarding the predominance of positive or negative outcomes associated with this experience. This study wants to give more clarity around this population, focusing specifically on teenagers between 11 and 18 years old. The following sections will present existing literature on families living with a disability of a child and will discuss the implications that such event has on members of the family, focusing on parents' experience in the first chapter and on siblings' experience in the second one. This work will adopt a prospective according to a systems psychology approach that presents family as a dynamic system proposing that what happens in a part of the system, for instance the disability of a child, has direct consequences on other parts of the systems, hence the other members of the family (Pavone, 2009). Thus, all the work evolves around this first conceptual perspective.

The first chapter will explore what happens in a family when a child is diagnosed with a pathology, disability or syndrome and especially how disconcerting it can be for parents who experience feelings of guilt, fear, anger (Bornstein e Venuti, 2013). It will also present a spectrum of different psychological disorders experienced by family members (Azar e Badr, 2006), and will present evidence showing maladaptive behaviours (Axelsson, et al., 2013) and chronic hardship, which is also imputed to poor social support as families with a disabled child often experience difficulties accessing healthcare services (Bertoli, et al., 2011), feel rejected by society and face economical struggles (Kish, et al., 2018) and as a consequence they often feel lonely in this journey with disability (Carlson, & Miller, 2017). Nevertheless, this chapter will also outline an important discrepancy in the literature: if initially researchers studying this phenomenon, mirroring society perceptions and beliefs, thought that having a child with a disability would result in only negative outcomes for a family, more recent studies have shown how disability can be a resource for families who have a functional cognitive adaptation as they can construct positive meaning and create stronger bonds between each other (Lodewyks, 2009) while enhancing their resilience (Bae et al.,2013). Starting from being more accepting in society Bogdan & Taylor, 1982), families can accept the disability of their child, going through a process that is often similar to what people grieving experience (Testoni, 2016), families can learn to be more resilient (Rolland & Walsh, 2006) and use coping strategies to cope with the challenges that a disability entails (Cuzzocrea, Larcan, Baiocco, & Costa, 2011).

Subsequently, the second chapter will present the literature on *siblings*, a term that will be used in italics when referring specifically to those children who have a brother or sister with a disability or a pathology. This chapter will highlight some of the major implications of being a sibling of a disabled child such as experiencing psychological distress (Breslau & Prabucki, 1987; Cadman et al., 1988), adaptation difficulties (Pit-Ten & Loots, 2000), school problems and decreased self-esteem (Giallo et al., 2012), early caregiving responsibilities (Cuskelly & Gunn, 2003), while perceiving the differential treatments adopted by parents towards the disabled child as they require major care due to their disability or pathology (McHale & Gamble, 1989). On the other hand, it will present some of the positive outcomes of being a *sibling* that research has outlined, such as being more resilient and having a positive thinking (Lazarus, & Folkman, 1984), developing prosocial behaviours towards others (Giallo & Gavidia-Payne, 2006), especially towards their sibling, being more empathetic and having an early social cognitive maturity (McHale et al., 1989), and even grow spiritually (Bae et al., 2013) Lastly, it will introduce the sibling's support groups, how they are structured, and what the benefits of participating are to one of these programmes.

Considering the inconsistencies of findings throughout the literature, this study will analyse, by using self and proxy reports, whether young adults between 11-18 years old experience significantly more internalising and externalising symptoms, such as somatic complains, withdrawal, conduct problems and peer relationship problems, compared to a control group. Furthermore, it will analyse the fraternal relationship

looking at its correlation with family cohesion-adaptability and parental acceptance-rejection. The study will conclude that although psychological distress is real and cannot be undermined by a more positive outlook on the siblings’ experience, some important positive aspects are also present such as a stronger family cohesion and adaptability, compared to the control group, which also correlates with a stronger fraternal bond. The implications of some unexpected findings related to the direction of the correlation between parental acceptance-rejection and fraternal bond will be discussed.

CHAPTER I

FAMILY FACING THE DISABILITY OF A FAMILY MEMBER

1.1 The Construct "Family" by a Systems Psychology Approach

Although psychology is a century old discipline, only in the last decades it has focused its attention in defining, exploring and explaining the concept of family and its complex dynamics through its lenses. Nonetheless, in only a few decades Psychology has broaden the understanding on family dynamics, showing how social changes shape the family identity and how family identity as well as the implicit roles played by the members of a family impact on the identity and well-being of an individual.

According to the *General Systems Theory* (GST), a theory developed in 1950 by the biologist Ludwing von Bertalanffy, all complex systems share the same general organising principles highlighting an inevitable interaction between the elements of a system which causes them to influence each other and functioning as a whole. This theory became soon a universal theory due its applicability to many other disciplines and fields, such as chemistry, psychics and social sciences. Psychology used the theory to broaden the conceptualisations on the family system. According to systems psychology, family is an articulated ecosystem made of complex interactions among parts – the family members - and by the interactions that these parts have with other systems, such as institutions and other societal entities, creating a continuous interconnectedness between people (Pavone, 2009). This dynamic entity is influenced by ever-changing transformations manifested in four different levels: individual, interpersonal, group and social. The individual level is characterised by the emotional, cognitive, and physical changes that each member of a group goes throughout their lifespan. The interpersonal level is given by the transformation overtime of relationships among family members. The group level refers to the adjustments due to important transformations of family composition, such as the birth of a child, the separation of parents, the illness or death of a member. Lastly, the social level refers to the changes within the family due to the transformation of their socio-cultural context (Togliatti & Lavadera, 2006). This stratification means that every minimal change in one level translates in an equal effect on the other levels, making them closely interdependent, therefore all are needed to be considered when focusing on one of the levels. This has important implications for this dissertation as implicitly suggests that in order to deepen our understanding on the well-being of siblings of disabled children it is necessary to take into account their family background, the interactions between members, changes in the family setting and socio-cultural transformations.

Every small change of a part determines a change of the whole system (Pavone, 2009) and its delicate balance depends on its intrinsic tendency to maintain homeostasis, an inner balance common in every mutable entity (Gambini, 2007). Thus, a family needs to adapt to morphogenetic processes, which are the continuous transformative movements typical of the system, while aiming to maintain its inner stability thanks to its morphostatic properties (Togliatti & Lavadera, 2006). According to Duvall, each member of a family faces different developmental tasks according to their developmental stage and this process influences inevitably how the other members are dealing with their own tasks (Duvall, 1988). Moreover, family is an open system functioning in relation to its socio-cultural context and it evolves throughout time (Walsh, 1982). The concept of family as an open system facilitates the understanding of its social dimension and the role that social environment plays when family faces life events throughout its lifespan (Togliatti & Lavadera, 2006). Family is indeed characterized by three important properties which are proper of an open system and these are known as principles of totality, retroaction and equifinality (Watzlawick et al., 1967). The principle of totality explains how any change of a family members due to external or internal inputs, influences necessarily other members and the family system itself. The principle of retroaction indicates the tendency of the interpersonal system to change or maintain the homeostasis. The principle of equifinality explains how the results of a given system depend upon the process of the system itself. On the basis of what has been presented, it is possible to argue that the disability of a child within a family does not only impact on the life of their parents but also on the life of the people close to them, such as their siblings, their grandparents and even the social settings in which the family system is collocated into. This shared bargain results in an unavoidable distribution of stress and disadvantageous experiences within the family system, and as a consequence it can become hard to find the positive aspects of having to share such a difficult experience.

Disability involves necessarily the whole family and as the whole family faces the consequences of the disability, it becomes itself an atypical entity. However, the action of sharing the experience is the most powerful resource as by using each member's strengths and capabilities it is possible to better confront the consequences of the disability. Therefore, it becomes necessary to work on both directions: on the one hand it is important to recognise as early as possible negative outcomes experienced by each member in order to support and prevent the outbreak of chronic issues, on the other hand however, it is fundamental to find the inner resources of each family member, aiming to reinforce them to aid the family through its inner potential and eventually learn to thrive in the face of adversity. With such prospects, a family sharing a disability can mutate from a "disabled entity" to a "resourceful entity" using the disability to its own advantage making the family more prepared and skilled than typical families in different domains.

1.2 The Birth of a Disabled Child

Becoming a parent is one of the most extraordinary adventures that a human being experiences. It changes a person's life from its core and redefines their identity. The book *"The birth of a mother: How the motherhood experience changes you forever*." (Stern, 1998), well describes these changes. It suggests that having a baby redirects a person's values, changes their priorities, preferences and pleasures, influences their closest relationships redefining their role within the family system and in society, and it awakens new hopes and fears. In other words, it changes the mental organization of primary caregivers, their "motherhood constellation" as Stern named it (1998). The birth of a child is a moment charged with conscious and unconscious expectations which date back to the time parents were children themselves, the way they were raised, their cultural and family background. Soon parents come to realise that these expectations are unmet as the child is not as it was imagined, and parenting is not as expected too. This acknowledgment can be at times very destabilising. Considering how shocking it can be facing parenthood in a typical situation, what happens if parents learn that their child has an atypical devolvement, is born with a chronic pathology or has a disability? It is disconcerting to the least as all plans and expectations made before birth fall apart (Bornstein e Venuti, 2013). Parents are never ready enough to hear that their child has a disability. Finding out that their child might struggle, suffer physically or mentally, or that will not have a typical development, it is a hard pill to swallow.

The term "disabled" describes the physical, sensory, developmental or cognitive impairments that can disrupt individuals at any point of their life, and can persist throughout their existence (Scherer et al., 2019). Disabled children face constraints in terms of physical, learning, and behavioral functioning that could be the result of a wide range of factors, from hereditary problems to neurological and developmental ones.

The research of the last decades on families with disabled children has shown that the birth of a disabled child has an irreversible impact on the family life with all members of the family becoming vulnerable to the new challenges that such experience involves. Nevertheless, research has also highlighted that as the saying goes "not every evil comes to harm", and that data shows a wide range of positive outcomes within the family life associated with the birth of a disabled child. In the two sections below, it will be presented how this unique shared experience affects all aspects of family functioning, looking at negative aspects as well as positive ones.

1.2.1 Stressors and Challenges of Families with a Disabled Child

Research on families with disabled children started to develop around the 50's with the major contribution of Bernard Farber, who in the 60's published three volumes focusing on how severe mental disability impacted the life of family members. He found that generalisations between families could not be made, however he found that for all families this phenomenon caused an arrest of the typical family life cycle and he tried to define common functional strategies that could be applied in order to maintain family integrity (1960). Another early contribution in this area of research is given by Mary Ainsworth (1972) who found that feelings of mothers of a disabled child are very similar, with the prevalence of feelings of guilt and rejection towards the child which results in the use of a wide range of defense mechanisms such as overprotectiveness and denial (Schonell, 1957).

The birth of a disabled child, or the moment of a diagnosis are events that nobody plans for or expects. Individual identities, family roles (Smith, & Samuels, 2021), family functioning, routines, must be re-constructed to care for the needs of the child (Iacolino, et al., 2016), which carries a heavy burden for the entire family (Gomes, 2020). The whole family system experiences forms of stress, and challenges that can lead to crisis and negative impacts on the quality of family life (Kandel, & Merrick, 2003). The impact of child disability on a family begins at birth or from the day of the diagnosis and it accompanies the family during the whole life, and families need to meet specific demands required to facilitate raising a child with special needs. Such demands are greater parental involvement, increased childcare, deplete physical and emotional energies, as well as time and economical finances (McCann, et al., 2012). For instance, parents often need to change occupation hindering their professional development (Brown, & Clark, 2017), or causing financial hardship to the family (Meyers, et al., 1998; Kish, et al., 2018). Mothers of disabled children often leave their job in order to commit to the needs of their child (Sorrentino, 1987). Furthermore, members often struggle to develop their own identity or get involved in social gatherings as (Baumgardner, 2019), progress on their education (Lara, & de Los Pinos, 2017), and their personal needs are put on hold to provide for the child in need (Naylor, & Prescott, 2004).

These day-to-day stresses and challenges affect the quality of life and functioning of the family. Families of disabled children find difficult accessing healthcare or special-need services, and coordinating with professionals to receive assessment, evaluations, and treatments for their disabled child (Bertoli, et al., 2011). They often lack social support, or experience negative responses from people within the community, as people may judge, reject, avoid, or exclude the family, which can lead to isolation and feelings of loneliness (Carlson, & Miller, 2017). Family members often deal with mental health issues, such as depression and anxiety (Azar e Badr, 2006) and report having a lower sense of well-being and life satisfaction, whereas siblings of disabled children may present psychological or behavioral problems (Axelsson, et al., 2013). Being a parent, family member, or sibling of a disabled child is overall significantly challenging as it requires an overwhelming amount of effort to overcome obstacles, maintain healthy relationships, and achieve emotional stability.

1.2.2 Positive Outcomes

Until the 80's research had biases towards disability in a family context associating the experience with only negative consequences, however researchers realised that it was not the full picture as many articles found many positive outcomes correlated with this phenomenon too. The reason for this initial bias was due to the assumption that the way families would handle disability would be maladaptive as it was too impactful for families and would eventually lead to pathological responses. For instance, they believed parents would most likely present personality issues and psychological disorders, whereas children would cultivate relational and behavioural problems. Nevertheless, studies have shown how disability can become a resource as families learn to be determined, resilient (McCubbin & McCubbin, 1996), with stronger bonds between family members (Burbidge & Minnes, 2014), and a more positive outlook in life (Lodewyks, 2009).

During the developmental stages of their disabled child, parents feel very satisfied and proud of every little achievement, making them feel more confident as their efforts to help their child achieving specific objectives were successful. Thus, the family experiences a maturation which goes in parallel with the development of their child. (Dall'Aglio, 1994). Moreover, siblings of disabled children grow an abundant set of positive characteristics compared to their peers such as social competence, appreciation for life, compassion, insight, pride and maturity (Bergmann, 1998). A qualitative study conducted in 1998 interviewing nine family units outlined 9 positive impacts of children with an intellectual disability on their families: source of joy and happiness, increased sense of purpose and priorities, increased spirituality, expanded personal and social networks, community involvement, increased tolerance and understanding, personal growth and strength, positive impact on community, family unity and closeness (Stainton & Besser, 1998)

Furthermore, a difference in the stress response between families has been found, with some disabilities impacting in a less negative way the family life compared to others. For instance, in a study it was found that families with children with Down Syndrome experienced significantly lower levels of total stress, child-related stress and stress related to parent-child interaction compared to families with other disabilities, such as genetic syndromes, cerebral palsy and pervasive developmental disorder (Smith et al, 2014). Across diagnostic groups of the study, parents all equally felt successful in their ability to stimulate their children's communications skills, confirming that these families are, as previously discussed, by normative and adaptive responses to stress (2014).

Positive and negative attitudes and perceptions of the disability of a child are often the result of negative biases towards disability ingrained in cultural beliefs which can negatively or positively influence the way a family faces this experience (Gupta & Singhal, 2004). As illustrated by Lodewyks (2009) in Figure 1 below, the child and its family (Microsystem) have the ability to adapt in a functional way to their experience allowing them to construct positive meaning and enhance their self-esteem. However, social attitudes, perceptions and beliefs about disability and its impact (Macrosystem) can potentially affect the ability of the family to cognitively adapt to their experience (Arrow 1). Therefore, some families may struggle to adapt to their situation partially due to the negative attitudes and perceptions held by their surroundings. Instead, other families adapt well to their experience in such a way that this has an impact on the environment as it challenges the misbeliefs and negative attitudes towards disability (Arrow 2) and help build a more affirmative and non-tragic understanding of it (Arrow 3). This non-tragic model about children with disabilities adopted by disabled and non-disabled people contributes to positive changes in the Macrosystem (Arrow 4) which can in turn affect the well-being of disabled children and their families giving them more positive perceptions and adaptations (Arrow 1).

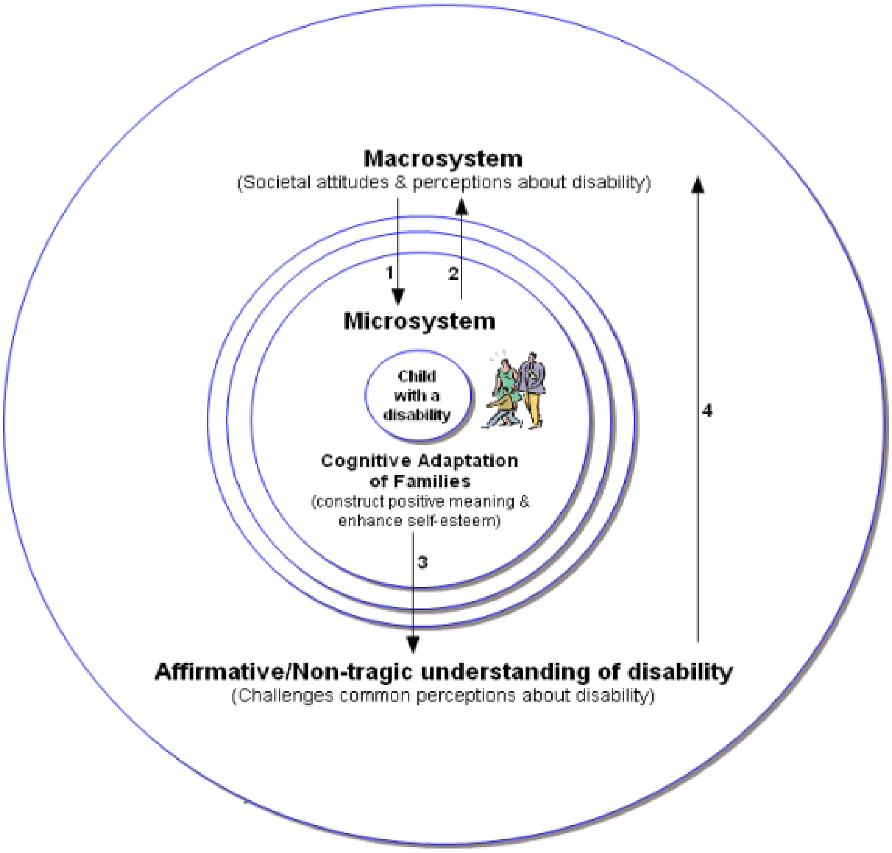

Figure 1 *Integrated conceptual framework adapted by Lodewyks (2009) from Bronfenbrenner, 1979.*

1.3 Accepting Disability

1.3.1 Conceptual Framework of Acceptance

In 1987, the researchers Taylor and Bogdan wrote an article named "*On accepting relationships between people with mental retardation and nondisabled people: towards an understanding of acceptance",* which gives a clear understanding on how the mentality of the time on disability was shifting from seeing disability, especially intellectual disability, as an obstacle to social and family development, to a more open view which considered disability a possible resource for the whole community. They proposed that the “labelling theory” on deviance developed in the 30’s could be applied to mental disabilities. This theory proposed that social groups create deviance by making rules, which if violated establish deviance and make those who break them “outsiders” (Becker, 1963).

The article developed for key insights on the matter: First, intellectual disability is a social and cultural construct since, like other forms of deviance, it is not an objective condition but rather a concept existing only in the minds of people who attach such labels to others (Bogdan & Taylor, 1982). Second, the label “mental retardation”, used at the time, carries with it a stigma as “*the label of mental retardation not only serves as a humiliating, frustrating, and discrediting stigma in the conduct of one's life in the community, but it also serves to lower one's self-esteem to such a nadir of worthlessness that the life of a person is scarcely worth living*" (Edgerton, 1967, p. 145, as quoted in Taylor & Bogdan, 1987). Third, labelling someone mentally retarded created a self-fulfilling prophecy (Merton, 1948). As a famous dictum states “*if men define situations as real, they are real in their consequences*” (Thomas, 1928, p.572, as quoted in Taylor & Bogdan, 1987). In other words, expectations on behaviours conforming to societal rules settles in the mind of people who are labelled as deviant and as a consequence they start acting according to these expectations. Fourth and last key insight of their article states that institutions and organizations designed to care for people with cognitive impairments reinforce and sometimes even create behaviour that further distances people with retardation from the broader community. These insights served as solid base to build their further implications on accepting disability in the wider community.

They suggested four main reasons which would motivate people accepting relationships with disabled people: family, religious commitment, humanitarian concern and feelings of friendship. For what concerns family, acceptance is often based on a sense of commitment and obligation towards the disabled family member. Parents often develop a set of beliefs that help them accept their child’s struggles turning negative situations into positive ones (Turnbull, et al., 1985). People who are religiously commited are motivated to seek relationships with people suffering from a disability as they see it as a blessing, and they believe that the same way Christ cared for the ones in need they are called to do the same. Similarly, people directed by humanitarian concern, believe that having a relationship with the disabled is good practice and for some is a way to tackle social injustice. Lastly, feelings of friendship usually are the results of one of the previous motivations, developing slowly into a more genuine and spontaneous form, which is liking and enjoying the company of the person with disability. Another important point brought up in their work is that once disabled members are starting to be accepted, the disability gradually becomes less salient in the eyes of their family and friends, and they begin to define the disabled person according to their qualities and characteristics (Taylor & Bogdan, 1987). Regardless the reason why people decide to form a meaningful relationship with disabled people, it is crucial to promote a caring and inclusive environment for them as it is thanks to the emotional support of the wider community and the self-esteem correlated to it that the individual who has a disability can learn to accept their own physical or mental state (Li & Moore, 1998).

1.3.2 Phases of Acceptance

After having considered acceptance of disability within a wider societal context, it is crucial to analyse the phases that families go through from the diagnosis of their child to its development into a young adult and find elements that help families maturing functional ways to deal with their new reality and learn to accept it in a positive way. Once a couple decides to start a family, both partners imagine what their life will be, they make mental representations of their future, try to have everything planned, even their children. They imagine their gender, have expectations on their talents and abilities, represent them based on their family history. Once they learn about the disability of their unborn or new-born child, they experience most times a real shock as disability is something they were not prepared for. The way they experience this news and the feelings associated with it are much comparable to the symptoms typical of the post-traumatic stress disorder (PTSD - Hollins & Sinason, 2000). After the communication of the diagnosis, parents often experience intrusive thoughts, they become avoidant, feel constantly alerted, struggle with insomnia, all symptoms common in PTSD patients (Pacella et al., 2013).

Communication of the news is the first crucial step of this long journey of acceptance. Thus, it appears crucial to communicate the news in an empathic, exhaustive and clear way, in order to allow parents to have a full understanding of what it has been said so that they can start processing it. Indeed, it has been shown that the level of satisfaction regarding the moment of the communication is directly proportionate to the quantity and the quality of the information given about the diagnosis of the child (Hasnat & Graves, 2000). The two main characteristics for an effective communication of the diagnosis are empathetic listening and comprehension (Graungaard & Skov, 2007). Having an empathic listening is fundamental when a professional figure gives a diagnosis as it enables to settle a trustful relation, it implies care for the family and it can help alleviate negative feelings such as anxiety, fear and uncertainty. Comprehension helps the family to find resolutions to their difficulties and allows preservation of a supportive relationship with the medical staff. Furthermore, positive politeness while communicating with parents of disabled children has been also shown to elicit adaptive emotional expressions in parents (Tremolada et al, 2011).

When parents are given a diagnosis of their child, they experience bereavement of the imaginary child they represented in their minds. It is not coincidence that delivering a poor prognosis to terminally ill patients, it implies the same kind of communicative skills as the emotions following the news are the same. In fact, delivering the "bad news" to families of a terminally ill patient – in literature referred as *breaking bad news* – has the same principles and aims of families of a disabled child: practicing "truth telling" - an open empathic communication with the patient and their family that allows the start of the processes of acceptance of the inevitable event (Testoni, 2016).

Therefore, considering the close interconnectedness between these two experiences, it is possible to summarise the path towards acceptance of the disability of a child with the "five stages of grief", a model proposed by the Swiss psychiatrist Elizabeth Kübler-Ross (1974), a pioneer of the near-death studies who elaborated this model for people dealing with anticipatory grief. This model, also known as DABDA, is composed of 5 stages, which do not follow a chronological order, but give a clear idea of how the journey of acceptance evolves: *Denial*, as not accepting what is happening. This first phase in parents dealing with a diagnosis of their child can mean rejecting what doctors have diagnosed and try to find evidence against the diagnosis, asking different opinions hoping to hear a different conclusion. A*nger* - strong negative emotions such as rage, fear, guilt, and resentment. For instance, after the diagnosis is confirmed, parents start feeling anger and resentment towards anything and anyone: the doctors who, according to the parents, have not done enough to prevent the situation and angry with the situation itself. *Bargaining* - attempting to negotiate with reality. In other words, parents try in every way to change the outcome of the diagnosis by making false hopes about the future, hoping that by making changes reality will change as well (Gregory, 2022). It is the phase in which people make a deal with a supernatural entity, for instance God, to heal their loved ones. This phase is also the phase of the of the "if only", a phase accompanied with feelings of guilt in which parents start thinking about what they could have done to avoid the situation and start feeling responsible for their child's problems, especially if the disability or pathology are hereditary or if it is the consequence of an accident. Frequently, mothers blamed themselves believing that they have caused the disability of their child during pregnancy (Migliore, 2011). *Depression* - losing hope and despair. Parents start to realise fully the reality and start to feel desperate, uncapable to face the situation and lonely. Finally, *Acceptance* - resignation of the inevitability of death (Testoni, 2016), which in the case of a child diagnosis of a disability it entails accepting the diagnosis of their child and learning to live with the new challenges ahead. The ability of parents to elaborate the trauma associated with the diagnosis of a child and convey positive attitudes towards disability are fundamental aspects which determines an appropriate elaboration of the siblings of the disabled child (Simeonsson & McHale, 1981; Scelles, 2003).

1.4 Resilience as a Determinant of Individual and Family Functioning

Severe pathologies and disability of a child or adolescent pose frightening challenges for a family and its impact reverberates to all system affecting each member and each relationship within the system. After the communication of the diagnosis some families start collapsing, and like a domino, all things in their life lose balance, family life deteriorates, and they struggle to find a new balance. On the other hand, some families not only manage to overcome difficulties and stay close to each other but even thrive (Weihs et al., 2002). A fundamental element determining these differences when facing such experience is familiar resilience as it allows a family to adapt to the sudden changes after a diagnosis is received. (Rolland & Walsh, 2006).

1.4.1 Definition and Determinants of Resilience

Resilience comes from the Latin verb "*resalio*" meaning literally spring back, rebound and it refers to the ability to "bouncing back" from difficult experiences with the ability to adapting well in the face of adversity, trauma, tragedy, and significant source of stress (Joyce, et al., 2018), allowing the individual to gain meaning in life and personal growth. Using a psychodynamic concept, it could be defined as the ability to manage regressive tendencies through progressive thrusts. Initially, in the 70's it was thought resilience was an inner quality of people, an ability that could not be leant or taught (Masten, 2014). However, in the 80's and 90's several studies showed how resilience is a dynamic process that allows to activate functional coping mechanisms and find inner resources and protective factors that transform a potential threat into an opportunity to find new growth and allow individuals to flourish again. Therefore, it is an extraordinary complex phenomenon determined by multi factors (2014). Indeed, the vast literature of the last forty years has suggested that there are multiple factors determining the onset of resilience and that these involve the person in their integrity, from an individual level to the environmental level, hence their family, community and culture (Fleming & Ledogar, 2008). The theoretical framework on resilience suggests that determinants of resilience can be divided in two main categories which are internal factors, also referred as internal assets, and external factors, which correspond to protective factors (Constantine et al., 1999). According to the six-domain model proposed by Daniel and Wassell (2002) the individual factors can be synthesised in: *social competence*, which is the ability to engage in meaningful interactions; *positive values*, which are strong guiding principles that allow an individual to make healthy life choices; *talents and interests* forming the complexity of a person. Some additional determinants frequently found in literature are also *self-efficacy,* which is the ability of the self to trust that its own abilities can dominate and control its own functioning and features of the social environment (Schwarzer & Warner, 2013); and *brain functioning*, in particular resilience is highly associated with the activity in the hippocampus, amygdala and prefrontal cortex (Hunter et al., 2018).

Whereas the main environmental factors include *education, friendships* and most importantly a *secure attachment*. According to Daniel and Wassell (2002) education needs to be intended not only as a process but also as a place to grow and as a group of people who teach and interact with the child; the interaction of these components enhances resilience in children (Ellenbogen et al., 2014). For what concerns friendships with peers, authors suggest that resilience is highly associated with having positive peer relationships and specifically good friendships (Werner, 2000) and that having friends can help lessen the effects of stress (Thompson, 1995). Lastly, the factor that appears to play the most crucial role for the development of resilience is an early sensitive caregiving as it reduces the effect of a toxic environment (Herrmann, 2021). Thanks to the secure attachment formed with the caregivers, infants learn to form meaningful relationships, self-regulate and grow a positive sense of self, which in turns allows them to grow a resilient mindset (2011). To further support this point, Rasmussen et al (2019), claimed that all determinants of resilience can be traced back to attachment experiences, suggesting that the quality of early attachment facilitates the development of resilience properties. Secure attachment does not only influence children and adolescents, but it influences parents and their parenting styles. Therefore, it is important to focus on these factors and create early interventions in order to work with families ready to take up the challenges of dealing with a pathology, disability or atypical development of a child. The most effective time to create intervention strategies is during the developmental age, as it is the sensitive period in which intervention works best (Gunnar & Fisher, 2006).

1.4.2 Family Resilience Framework

A family resilience framework is grounded in the recognition that through crisis and unrelenting challenges, the family system manages to move on thanks to functional family processes allowing adaptation of family members and new balance for their relationships (Rolland & Walsh, 2006). The family’s ability to address an event such as the disability of a child and overcome the following crisis is linked to the availability and effective use of resources and coping strategies (Cuzzocrea, Larcan, Baiocco, & Costa, 2011). Studies on families with a disabled child demonstrate resilience in the face of challenge. For instance, the study of Farrell, Bowen, and Swick (2014) examined the support experienced and the perceived reliance of mothers with a child who has special needs and their spouse in the army. These mothers significantly experienced less support than their counterparts and yet were equally resilient. Formal and informal network support was associated positively with greater resilience.

Key processes for resilience enable family to rally in times of crisis, buffering stresses and gain adaptation (2006). The research-informed family resilience framework adopted by Walsh (2003) suggest useful guiding interventions to target key processes for the strengthening of family resilience and outlines three main objectives that clinicians need to work towards. First, family can better master challenges after a diagnosis if clinicians can properly inform them on the pathology, its consequences and make a plan of action. A combination of biomedical and psychosocial approaches (Rolland & Walsh, 2006). Second, psychologists need to strengthen relational resilience by making sure there is a functional family unit. Indeed, research suggests that there is a positive association between a strong bond within family members and the management of a chronic-disease or disability (Primomo et al, 1990); hence strengthening this bond will enhance family members' well-being and as a consequence family resilience. Lastly, it is important to encourage developmental trajectories that will help families to fit the demands of the disability trying to avoid the emergence of developmental issues (Rolland & Walsh, 2006), especially for the siblings of the disabled child. In addition, it is also important that families work towards an awareness of their beliefs and multigenerational legacies influencing their perspective on health problems and health care providers in order to free themselves from possible biases which could cause additional worries and further complicate their experience with a disability.

CHAPTER II

SIBLINGS OF DISABLED CHILDREN

2.1 The Forgotten Children

Once research has started to analyse the experience of families dealing with a chronic pathology or a disability, it has shown the huge impact that this experience has on the families of disabled children and it has focused on the effects of the disability on the disabled child and their parents, as they are responsible for their upbringing, wellbeing, and medical assistance and it has important implications for their everyday life. Only recently research has started to shed some light on the feelings, experiences, and development of the siblings of disabled children, individuals who are also part of the family unit but who were not considered by previous literature, and for this reason have been named the *forgotten children* (Hanold, 1989) or the *invisible children* (Naylor & Prescott, 2004).

First studies on fraternal relationships have been conducted in the 60's with the intent of considering the impact of this special relationship on the structuring of individuals' personality and the development of specific characteristics such as social, cognitive, and emotional skills, with an important focus being posed on the role of gender differences and birth order (Hetherington et al., 1994). Between the 70's and 80's studies on fraternal relationships have moved their focus from the impact of this relationship on the individual to the relationship itself and how familiar and social environment in which this bond was formed would influence it (Stoneman & Brody, 1993). It is around this period that researchers started to take in consideration how disability of one of the two siblings could exponentially influence the relationship and the general development of both children. Initial studies have looked at this phenomenon analysing it according to a quantitative approach, which has not allowed to envision the problem from the personal subjective perspective of the individuals involved (Trinceri, 2016). As a result of this, most studies have found a polarisation of the results towards a negative, and at times pathological, picture. It is only around the 90's that studies have started to look at the experience of siblings though a qualitative lens which has allowed to gain a wider understanding of what this experience means for children, taking to consideration the positive aspects too.

2.2 Implications of Having a Disabled Brother or Sister

Having a fraternal relationship with a person who has psychical, relational, emotional, or cognitive difficulties is an unavoidable challenge that *siblings* need to face throughout their life, and it affects inevitably their development. Indeed, the fraternal bond is a huge contributor of the formation of later relationships and the formation of the identity of an individual (Caliendo et al., 2020). In the last decades, an increasing number of studies have found a substantial number of *siblings* dealing with emotional and behavioural disorders (Pit-Ten & Loots, 2000), however most of these studies have analysed families characterised by a child with cognitive disabilities, therefore findings could not be generalised to *siblings* of physically disabled children or children with chronic illnesses (Sloper & Turner, 1993). On the other hand, there are studies that have found positive outcomes related to having such experience for these children (Schulz, & Sherwood, 2008; Bae, et al., 2013; Farrell, & Krhan, 2014). What these mixed findings suggest is that growing up with a sibling with a disability or a pathology has both positive and negative effects (Fisman et al., 2000). However, while negative effects are rather immediate the positive outcomes are often visible when the *sibling* grows up into adolescence or even adulthood (Rossiter & Sharpe, 2001).

In the following sections, this study will provide an overview related to the findings related to negative and positive impacts on *siblings* life, showing the inconsistency and controversy of findings (Pit-Ten & Loots, 2000), while considering the role of siblings within the family system and propose support groups as a powerful tool to enhance their self-esteem, give them a better understanding of their experience, while sharing it with other children experiencing a similar situation and give them space to share their emotions, their preoccupations and fears (Valtolina, 2005).

2.2.1 Difficulties and Psychopathological Concerns

Considering the negative biases towards disability often ingrained in cultural beliefs of western countries (Lodewyks, 2009) initial research on *siblings* has focused its attention to the psychopathological outcomes of having a brother or sister who has a disability or a pathology. Many studies have brought to the attention a multitude of problems regarding the behavioural and psychological spheres. Studies have found that *Siblings* can develop severe adaptation difficulties (Pit-Ten & Loots, 2000; Fisman et al., 2000) such as school problems, decreased self-esteem and social stigma (Giallo et al., 2012). These children build an idea of who they are based upon their experience of continuous stress within their family environment (Dondi, 2018). Furthermore, it has been reported a higher rate of social impairments, internalising problems such as depression and anxiety (Breslau & Prabucki, 1987; Cadman et al., 1988) and externalising problems, such as aggressive behaviour and problems in social and peer relationships (Breslau et al., 1981; Lobato et al., 1987), a lower level of life satisfaction (Sommantico et al., 2020a) and higher closeness and worries (Sommantico et al., 2020b). Studies have also highlighted a higher occurrence of psychosomatic illnesses and problems in school (Tew & Laurenc, 1973). According to literature healthy siblings of disabled children are the group most at risk of facing mental disorders and consequently have difficulty in the school setting and in interacting with peers (Caliendo et al., 2020).

The feelings recurring amount these children are shame to be part of an atypical family, sadness due to the scarce attention they receive from their parents, feelings of guilt, fear that what happened to their sibling could happen to them, feelings of loneliness and low self-esteem. These feelings are however balanced by feelings of proudness and enthusiasm for the achievements of their siblings as they feel they contributed by helping them reaching certain goals (Farinella, 2015). Although the literature does suggest an important risk for these children to develop a wide range of different problems in different areas of their life, it is fundamental to recognise that through a good adaptation of the family, and especially of the parents, healthy siblings can also adapt successfully to the disability or illness of their sibling without facing psychological maladjustment. Indeed, Lobato and colleagues (1988) suggested that there is no uniform relationship between a child’s impairment and psychological maladjustment of their siblings, thus it is fundamental to support the family and the healthy sibling through this journey and make sure to decrease the impact of other factors enhancing the possibility of facing negative outcomes, such as parental neglect and societal rejection, to enable the child to have the best possible development.

2.2.2 Parental Differential Treatment of Siblings

Research has suggested that as a consequence of the extensive amount of care parents need to give to their child with a disability, the time to care and support their healthy siblings reduces drastically, which results in a worsening of psychological functioning (Powell & Gallagher, 1993). Differential treatment of the children is considered a factor influencing sibling adaptation (Pit-Ten & Loots, 2000). Studies have found a correlation between differences in parental treatment and psychological functioning of the children (Powell & Gallagher, 1993). For instance, McHale and Gamble (1989) reported that the differential treatment given by parents to their disabled and typically developed children related to depression and anxiety to the group of typically developed children. Another study found that mothers of children suffering from cystic fibrosis spent more individual time with their younger chronically ill children in play and mealtime activities than their older healthy siblings and rated time spent with the older child more negatively (Quittner & Opipari, 1994). The authors suggested that this would drastically enhance in *siblings* the risk of experiencing the negative effects of differential treatment. Similarly, a study conducted in 1983 on siblings of children with spina bifida found that they often develop feelings of neglect as a result of the amount of parental attention and care for the child with a disability (Von der Dunk 1983, as cited by Pit-Ten & Loots, 2000)

2.2.3 Role Cross-Over and Early Parentification

Studies focusing on siblings’ life experience have found that these children not only receive less amount of care compared to their disabled brother or sister, but they often have to care and be responsible for their disabled siblings themselves. This does not only happen when the healthy sibling is older but also when he or she is younger. Indeed, among families who have a chronically ill or disabled child, it is very common to witness a phenomenon named “role cross-over”. This phenomenon occurs when younger siblings surpass their disabled brother or sister in developmental task and are cognitively more competent than their sibling (Lobato, 1993). Therefore, as soon as younger siblings reach a certain amount of autonomy and independence, they will play a role that is not typical for their age as it is invested of expectations and adult responsibilities (Farinella, 2015). For instance, studies have shown that regardless the birth order, *siblings* take on roles of assistance and care already in early childhood if compared to their peers (Cuskelly & Gunn, 2003). When children are involved in all aspects of their sibling’s disability or pathology, they are invested in many responsibilities and they are to some extent made accountable for the well-being of their sibling, this phenomenon is quite common among these families that healthy siblings could be seen as the “guardians” of their disabled siblings (Kaës, 2008).

In addition, it has been suggested that these children offer spontaneously and without apparent difficulty support to their disabled siblings, by offering physical closeness and by helping them and their parents in everyday tasks (Seligman & Darlin, 2007), going through a process called “parentification”. The term parentification is used when a child engages in parental duties and responsibilities to care for their siblings or parents (Caruz, 2006). In the early definition of childhood parentification, the term was seen as a violation of family boundaries in which a child could make decisions for the family with very little or any parental support (Minunchin et al., 1968). Children who have a brother or sister with a disability have often reported that in the personal accounts of their experiences at home that they have more in-home responsibilities compared to their peers (Klein, 1972; Sullivan, 1979). This process of parentification can occur unintentionally or it is actively elicited by parents who see their healthy child as a good source of help. These children start to feel responsible to solve problems and discontent within the family and oftentimes feel satisfaction in playing this role. However, it has been suggested that these feelings are often introjected and non-intentionally activated in the child, who instead of living an authentic maturation of the self, is often building a false self, which is due to a superficial adaptation of the situation and a reactive formation which hides a profound sufferance (Ferrari et al., 1994). Indeed, it has been proposed that caring behaviours towards the disabled sibling and mature behaviour are a defence mechanism that serve as a way to gain some parental attention that is usually directed towards the disability of the sibling (Tesio, 2000). Research has tried to understand if variables such as gender and birth order affected somehow the process of parentification without finding a common clear answer. For instance, some studies have found no significant difference in terms of sharing responsibilities between gender (Scelles, 2005). On the other hand, some studies have highlighted that older sisters seem to be more invested in responsibilities regarding the care of their younger disabled sibling compared to older brothers (Stoneman et al., 1991) and as a result of this they feel isolated and lonely (Ferraris, 1994).

Regardless the impact of specific variables in the emerging of this phenomenon, researchers have proposed that parentification of siblings of disabled children does not directly translate to the exhibition of higher rate of psychological and emotional impairments (Lobato, 1983), on the contrary this phenomenon could also stimulate a series of positive outcomes. For instance, healthy and adaptive parentification is considered acceptable and age-appropriate whereas infantilised and destructive parentifications are considered pathological and detrimental for the child's accomplishment of developmental tasks (Chojnacka & Iwański, 2021). Parentification can have different forms and different levels of intensity, it can be "emotional", in case children serve as emotional support to their parents, and "instrumental" when they are responsible for the care of their siblings (Owsley, 2019). It can stimulate positive outcomes as it can strengthen the fraternal relationship and it can reduce conflicts and rivalry between siblings (Tomeny et al., 2017). In addition, it can lead to the development of interpersonal skills and it can enhance *silbings* resilience (Owsley, 2019). Lastly, it can reduce feelings of distress and anxiety when *siblings* become adults (Tomeny et al., 2017).

2.3 Positive Aspects of Growing up with a Sibling with a Disability

Past research on families with children with disability has focused predominantly on the negative outcomes of having a child with a disability, with positive impacts on the family regarded as parental denial of the situation that led to the fabrication of positive aspects, or that the presence of negative outcomes implied the absence of positive outcomes (Stainton & Besser, 1998). However, recent empirical research on the positive contributions of children with disabilities has revealed several positive impacts on the family and furthered the understanding of what life is like for a family with a disabled child in all facets.

Shifts in family structure and roles due to having to care and support the disabled child, for example, has shown an increase of intrapersonal orientation of family members (Beighton, & Wills, 2019). Siblings of the disabled child may have to learn how to take care of themselves and how to help support their disabled sibling. As a result, they must develop early on an understanding of themselves and others, as well as develop skills associated with positive thinking, spirituality, prosocial behaviour, motivation, proactiveness, self-managing, and problem-solving, which are improvements in the personal qualities and character of the sibling and strengthen their ability to communicate and work with others in the world successfully. In other words, growing up with a sibling with a disability does not only involve negative impacts on the family but can enrich and enhance the quality of life for their siblings and members of the family in a multitude of ways.

2.3.1 Positive Thinking

Positive thinking is the human ability to be optimistic and maintain a positive attitude that can help overcome challenges and improve one’s health by reducing stress, depression, and anxiety (Naseem, & Khalid, 2010). Park’s Meaning Making Model (2013), an extension of the framework of the transactional model (Lazarus, & Folkman, 1984), suggests that for siblings of a disabled child to cope they might reframe their situation and adverse events to form more positive meanings about their life and experiences. In other words, the process of coping via positive thinking can lead to adversarial personal growth as siblings of a disabled child takes on a perspective in which they see their situation and caregiving role as an enhancement to their lives (Maercker, & Zoellner, 2004). In the caregiving literature, it is in fact well documented that family caregivers who cite positive aspects of the experience, report better wellbeing, mental health, and family adjustment (Díaz, et al., 2020; Otis-Green, & Juarez, 2012). Furthermore, family caregivers report that caring for another gives them a purpose, satisfaction, sense of accomplishment, boost their self-esteem, strengthens their relationships with others, and gives them the opportunity to develop new skills, abilities or career opportunities (Schulz, & Sherwood, 2008).

2.3.2 Spiritual Growth

Spirituality in the sense of beliefs about oneself, others, or 'God', facilitates acceptance of what cannot be changed, and helps deal with obstacles by encouraging planning, empathising, and communicating with others to change things that can be changed (Dyson, et al., 1997). Benefits emerging within the academic literature on spirituality offers meaning, hope, and connectedness with others that siblings can utilise to combat the negative aspects of living with a disabled child in the family (Parker et al., 2011). The presence of a disabled child has also accounted for personal transformations in terms of positive traits, such as inner strength, confidence, empowerment, and relational transformations in terms of attitudes towards other people, such as openness, supporting and advocating for others (Lodewyks, 2009). Siblings of a disabled child may attempt to improve themselves to control or minimise negative impacts. According to Cognitive adaptation theory (Taylor, 1983), they might focus on making positive changes, and search for a greater meaning in their lives. This process of adapting to the event of a disabled child and changes that comes with it enables the sibling to recover spiritually by making self-directed and self-enhancing evaluations. As they adjust their behaviour and cognition to overcome challenges this process can help them grow and benefit from it in the present and in future adverse events with increased awareness, resilience, and coping strategies (Bae et al., 2013; Farrell, & Krhan, 2014).

2.3.3 Social Cognitive Maturity

Given that a family of a disabled child may give additional care, attention, and preferential treatment to the disabled child, the sibling may experience feelings of exclusion or isolation. On the other hand, however, as the siblings adjusts, family dynamics leads to greater family closeness instead. Furthermore, the burden of sibling caregiving provides an opportunity for social cognitive maturity as they deal with problems, take on family responsibilities, and contribute to the household as a member of the family (McHale et al., 1989). As a result, siblings raised in a family with a disabled child can benefit from increased family closeness, social cognitive maturity, as well as responsibility, tolerance, emotional regulation, and independence (Pit-Ten & Loots, 2000).

2.3.4 Prosocial Behaviour

Siblings of a disabled child often exhibit higher levels of prosocial behaviour due to regular and frequent social interactions or encounters with their disabled sibling in which they help their disabled sibling in the form of custodial care, emotional support, physical assistance, and contribute to their learning process (Hannah, et al., 2005). For example, they may try to demonstrate to their disabled sibling how to behave correctly and modify their actions, comfort them, and monitor their safety and wellbeing. As a result, an enhancement in the sibling's positive attitude and empathy towards others, altruistic tendencies, and compassionate behaviours can be observed (Parfenov, & Bedwell, 2020; Perenc, et al., 2015). In other words, the presence of a disabled child in the family contributes to the development of greater prosocial capabilities of their non-disabled sibling.

According to Giallo and Gavidia-Payne (2006), the extent to which a disabled child positively impacts the prosocial behaviour of their sibling depends on the sibling's perception of their brother or sister daily difficulties, such as interacting with others, getting enough sleep, managing to complete simple tasks, or feeling positive. Furthermore, recent research indicates that siblings with high levels of empathy benefit from stronger fraternal bonds, although the effects are age sensitive and confounded by when the typically developed sibling lacks an understanding about the disability (Green, 2013). Consistent with the literature is the finding that the ability for *sibling*s to adjust to the event plays a significant impact on whether the situation can be viewed in a positive manner and yield beneficial outcomes, with *silbings* helping balance the demands of a disability and ease adjustment (Kaminsky, & Dewey, 2002). Nevertheless, encounters with their disabled sibling offer a rewarding opportunity that develops their social skills and understanding of relationships (Knott, et al., 1995).

Nevertheless, throughout the literature some inconsistencies have been found according to whether siblings of disabled children would exhibit more prosocial behaviours compared to children who do not have a sibling with a disability. For instance, the study of Kaminsky and Dewey (2001) reported that fewer prosocial behaviours were visible in siblings of autistic children compared to a control group. However, they also found less competition and fewer quarrels within the fraternal relationship. They suggested that the type of disability is implicated when measuring prosocial behaviours of siblings of disabled children. Similarly, De Caroli and Sagone (2013), found more negative social attitudes and negative representation of their autistic siblings compared to siblings with a brother or sister with Down's syndrome or intellectual disability. The study of Smirni and colleagues (2019) comparing the interactions of fraternal couples characterised by the presence of an autistic child or a child with Down's syndrome, found that autistic children spent less time with their sibling, exhibited a smaller repertoire of prosocial behaviours. On the other hand, studies have also suggested that having a sibling with autism can enhance prosocial behaviours, even if autistic children still show less imitation and antagonistic initiatives (Knott et al., 1995), or even equal prosocial behaviours of a control group in a sample of children between 3 and 9 years old (Caliendo et al., 2020).

Caliendo and colleagues (2020) suggested that the controversial results found in literature can be partially explained by the different research hypotheses of the studies or some methodological problems such as the lack of an appropriate control group, indirect measures provided by parents and teachers and the retrospective nature of some studies. Despite the variability of the results, empirical evidence gathered does suggest a significant impact of a disabled child in a family on their siblings' prosocial behaviours (2020). What it is clear from this summery is that age, birth order and type of disability seem to part of the determinants impacting the fraternal relationship and for this reason the next sections will consider their impact according to what has been reported by literature so far.

2.4 The Fraternal Relationship

The fraternal relationship invests a fundamental role in the psychosocial development of an individual. It is the longest relationship people experience, and it is characterised by everchanging transformations depending on the different evolutionary stages of a person's life. During adolescence it is a very predominant relationship, with strong emotions associated to the other person, both positive and negative. During the beginning of adulthood, it usually becomes less impactful in a person's life, before becoming meaningful again when people get older. Generally, it can be considered a friendship-like relationship in which people are bonded according to their will and their choices more than for sense of responsibility or duty. A well-functioning fraternal relationship is fundamental during the developmental age as it enhances social competence, it allows to manage functional conflicts in the adult age as it allows to recognise the importance of interpersonal exchange (Valtolina, 2005), positive adaptation in life (Kitzmann et al., 2002) and a better psychological well-being throughout the life cycle (Branje et al., 2004). It stimulates the development of different abilities such empathy, perspective-taking and problem solving (Dunn et al., 1991). For this reason, it becomes apparent how fundamental having a healthy bond is during the early stages of life for the development of a socially competent adult and it highlights the intrinsic problems associated with being an only child, as social isolation and problems maintaining relationships are more frequent in children who do not have a sibling. On the other hand, it becomes clear that the fraternal bond per se can assume different roles according to its characteristics as it can be a protection factor if it is stable and functional, whereas it can represent a risk factor if such a relationship is inadequate and hostile (Kitzmann et al., 2002). Nevertheless, when considering this bond, it is fundamental to also take in consideration the cultural background and the family context in which the relationship is formed (Stoneman, 2005).

Withing the initial framework delineated, it is now necessary to consider what changes in the relationship and what are the implications of having a sibling who has a disability or a pathology. Although siblings of a disabled child may experience higher levels of stress from the relationship due to functional difficulties in the interaction, emotional tiredness and development difficulties arising with siblings' new responsibilities, research has also indicated greater family closeness, higher levels of satisfaction, a less conflicted relationship, and stronger bond between a typically developing child and a disabled child (Fisman, et al., 1996). In order to have an understanding of this very special relationship between a dyad characterised by the disability of on the two siblings, the following sections will consider all determinants influencing its development and as a consequence the well-being of *siblings*, starting from the internal factors within the dyad and ending with the external factors influencing the relationship positively or negatively.

2.4.1 Internal Factors

The internal factors are siblings' characteristics directly impacting the fraternal relationship such as gender, age, age-spacing, birth order, type of disability, severity of the disability and characteristics of the relationship itself. Literature has mostly focused on the impact of gender and birth order in the fraternal relationship, and they have been often analysed as one interconnected variable. For instance, it appears that there is a greater negative impact of the disability on the healthy sibling if they are female and first born (Ferraris, 1994). On the other hand, males and second born seem to adapt more easily to the disability of the sibling as they are not as involved in the care of their disabled sibling (1994). Cuzzocrea and colleagues (2014) has suggested that for first born children the fraternal relationship is more stressful in their tendency to become overprotective of their younger disabled sibling and demonstrate an early maturation and an exemplar behaviour in order to support the family, resulting in neglecting their own needs.

Nevertheless, finding on the impact of birth order are not so unanimous as studies have also found a neutral effect (Grissom & Borkowsky, 2002), whereas gender seem to have a more stable impact on the adaption of *siblings* with female having higher perception of self-efficacy resulting in a greater impact of the disability of their brother or sister in their life (2002).

Another factor that has been researched in the last few years is the type of disability and its associated level of cognitive and physical impairments as it has been found to have a fundamental role when studying the relationship between siblings. This is due to the fact that it can highly affect the way the healthy sibling perceives their brother or sister and it can enhance or reduce their adaptation on their experience as siblings of a disabled child. For instance, if the pathology or the disability of a child are very severe, it can induce a high level of distress and a lower level of adaptation in their healthy sibling (Ferruzza et al.,2019). Physical and motor impairments can be an obstacle during the play time of the dyad, as activities they can do together are greatly restricted. Nevertheless, distinctions between this group needs to be made as for example sensorial disabilities, such as blindness and deafness, do not significantly compromise the emotional involvement and bond between siblings (Valtolina, 2000). For what concerns cognitive impairment, studies have also shown that playtime is reduced by the difficulties disabled children have to understand games and efficiently interact with their siblings (Stoneman & Bordy, 1993). Furthermore, dyads in which there is a sibling with autism have been found to have difficulties in relating to each other and communicating adequately as one of the main characteristics of autism are poor social communication and interaction skills resulting inevitably in an impoverishment of the quality of the relationship (Fisman et al., 2000). Whereas dyads in which one of the sibling has Down Syndrome seem to have higher adaptability, less stress and a better relationship compared to dyads in which one of the child has other disabilities (Hodapp, 2007), and even compared to dyads of typically developing children (Cuskelly & Gunn, 2003).

2.4.2 External Factors

External factors are those characteristics affecting indirectly the fraternal relationship. Social factors such as social economic status (SES) and social support impact this relationship as they affect the stress level within a family unit resulting in lower adaptation of healthy siblings (Williams et al., 2002). This correlation is however mediated by the level of parental stress and the general family functioning (2002). Indeed, parental stress is recognised as one of the most relevant factors when considering the adaptation of *siblings* (Amato & Flower, 2002). Family factors such as family coping strategies, resilience, and effective communication, can effectively influence the perspective that a healthy sibling has on their life experience. Parents' response and adaptation to the disability of their child (Stoneman et alk, 1994) is an important factor in siblings' adaptation, as the way in which parents cope with raising a child with a disability will partially determine the sibling adaptation to their sibling disability (Pit-Ten & Loots, 2000). For instance, a study found that both children with rheumatic diseases and their siblings experience more psychological and physical problems if their parents suffer from medical symptoms such as depression (Daniels et al., 1987). In the study, positive adaptation of both children was facilitated by family cohesion and open communication (1987). Furthermore, research also suggests that parents demonstrating acceptance towards the disability of their child and conveying positive attitudes towards their child results in their healthy child adopting the same behaviours (Tew & Laurence, 1973; Simeonsson & McHale, 1981). Moreover, the warmth and equity in which both healthy and disabled children are treated by their parents is associated with the way siblings interact, with high levels of parental warmth and affection positively associated with a stronger bond between siblings (Stoneman et al., 1994). Lastly, the ability of parents of effectively elaborating the trauma associated with the diagnosis of their child (Scelles, 2003), how much they are open to discuss about it with their children, their way to talk about the disability to their healthy child affects consequently the way the children will elaborate it and the way they will interact with their disabled brother or sister (Fisman et al., 2000).

2.5 Siblings' Support Groups

In the 1970s, research on the life of families with a disabled child was well-documented with the numerous negative impacts that a disabled child can have on their family, specifically the demands of having a disabled child and degree it affected family dynamics, such as requiring greater care and attention (McCormack, 1978). However, it was not until the late 20th century, that light was shed on the experience of non-disabled siblings, one of which often suffered due to the disabled child having priority and precedence over everything else (Dodd, 2004). As documented in the sections above, siblings of a disabled child can experience less parental attention, unequal treatment, lack of friendships, less opportunities to take part in interactions with the 'outside world', and greater involvement and responsibilities (Hastings, 2003; Sharpe, & Rossiter 2002; Wolf, et al., 1998) and as a result are more likely to be emotionally distressed, anxious, withdrawn, aggressive, dominant, trying to find ways of coping, and encountering problems adjusting (Russell, et al., 2003; Nixon, & Cummings, 1999; Summers, et al., 1994). In other words, there is a clear signal that siblings of disabled children require help.

Sibling support groups focus on identifying the needs of siblings, minimizing the negative psychological effects, helping them adjust, improving their wellbeing, and enhancing positive outcomes (Hartling, et al., 2014; Hewitt-Taylor, 2008). Sibling support groups aid by facilitating the siblings' ability to receive emotional and social support, educational resources, and by growing their social network that has shown to help build resilience (McLinden, et al., 1991), well-being (Smith, & Perry, 2005), and reduce anxiety (Houtzager, & Grootenhuis, 2001). According to a guide for conducting a support group for siblings of disabled children, it is suggested to have two main objectives: decreasing the negative effects experienced by siblings such as feelings of isolation, embarrassment, anger, resentment, neglect, guilt and behaviours that could compromise the psychological well-being of the sibling such as overachieving tendencies and increased care-taking responsibilities; while enhancing the positive effects such as social competence, maturity, competence, pride, insight, appreciation and compassion (Bergmann, 1998).

In a support program educating both siblings and parents in living with a disability and the difficulties that come with such experience, Evans and colleagues (2001) reported that siblings became more informed, felt more confident, had better interactions with their family, and were more engaged as caregivers to their disabled sibling. Another sibling support group mixed children with similar experiences resulting in increases in well-being, socialisation, coping strategies, and knowledge about disabilities (Burke, & Montgomery, 2000). There are several initiatives that have been proposed in the last years to help siblings elaborate on their experience, while making them encounter other peers who share a similar experience. Meyer and Vadasy (2008) for example, has proposed a programme named "sibshop" for *siblings* between 8 and 12 years old, with the objectives of giving them the opportunity to meet peers with similar experiences and socialise while sharing experiences and learning coping strategies to deal with certain problems proper of the experience of living with the disability of a brother or sister. A similar programme for the same age group has been proposed by Strohm (2006), with the difference that is articulated in 6 meetings of two hours and has different professional figures managing the meetings. This programme has the objective of alternate moments of fun with moments of help by exploring and learning to comprehend better the experience of the *siblings.* Another effective solution to support siblings has been shown to be the self-help-groups, groups of only siblings who exchange experiences and support each other. These groups have the main objective of contrasting the belief that siblings experience a condition that is unique to their life by making them confront with other people living a very similar experience and feel similar emotions (Farinella, 2015).

Professional figures such as medical staff, psychologists, and teachers can also provide support to the sibling of a child with a disability by helping them understand how to interact with their disabled brother or sister, resolve conflicts, care for them, and comprehend why they are suffering (Valtolina, 2005). The ability to obtain support from others is a valuable resource that can enable siblings to find ways to deal and adjust to the high levels of stress, and emotional dissatisfaction that exists, especially at the beginning. With access to a support group siblings may reach a point of stability that allows them to aid and support the family by caring for the disabled child at home, which can have a compounding effect as this can benefit the family's overall wellbeing (Venuti, 2022). Ideally, gaining awareness and essential knowledge regarding the disability and learning the relevant skills to care for their disabled sibling would help positively transform the situation and recognise the benefits of having a disabled sibling (Evan, et al., 2001). Once *siblings* go through a maturation process and begin questioning whether they can have their own future and independence, guiding them in the realisation that the event of having a disabled sibling is not disastrous, is vital to begin the healing process and move forward (Valtolina, 2005). Post-project evaluations have shown that these programmes have numerous positive effects on participants due to the benefits of sharing life experiences with other *siblings* (Trinceri, 2016).

CHAPTER III

DISSERTATION PROJECT

3.1 Overview and Hypotheses of the Present Study

Although the literature on *siblings* has recently produced numerous articles on this area of research, it has not yet provided a clear picture on how *siblings* going through their adolescent stages experience and are affected by the disability of their brother or sister. Thus, the study general aim is to investigate the well-being of *siblings*, the emerging of psychological and social distress while controlling for family dynamics, since psychological models have highlighted how the environment in which an individual grows into has direct consequences on their development. The results will be compared to the experience of a control group of peers who do not have a sibling with a disability but share socio-demographic characteristics. The data will be gathered using standardised self and proxy reports and descriptive statistical analysis, correlational analysis as well as t-tests will be carried out. This research will focus on teenagers between 11 and 18 as adolescence is a critical stage of life, in which young adults face a vast spectrum of emotions due to their physical, hormonal, neurological and cognitive changes.

More specifically, research has not yet given a clear direction on whether a disability of a child impacts positively (Lobato 1983; 1995) or negatively (Balottin et al., 2006) the general well-being and mental health of their siblings. Therefore, this research first aim is to present a clearer picture by exploring if in the research group there are trajectories directing towards relevant psychopathological disorders as well as maladaptive functioning and social difficulties compared to the control group. It is hypothesised that the research group will have more significant psychopathological problems, maladaptive behaviours and social difficulties compared to the control group.

Secondly, the research will analyse whether the relationship between siblings is influenced by the disability of one of the two comparing it with the control group which is not characterised by a member with a disability. It is hypothesised that a non-functional relationship between siblings will correlate negatively with healthy family functioning in both groups, with the research group having the least problems in the relationships with their disabled brother or sister and their parents, as literature suggests that disability can enhance their relationship.

3.2 Methods

3.2.1 Participants

A sample of 630 adolescents of different Italian regions participated in the study (356 females, 272 males) of which 51% (N=322) belonging to the research group and 49% (N=308) belonging to the control group. The inclusion criteria for participating in the study were the following: in both groups participants had to be between 11 and 18 years old with at least a sibling of any age, however in the research group this sibling had to be with a disability. The control group was created by matching age, gender, and birth order of the participants of the research group. Due to these criteria, data produced by 44 participants was excluded as they did not meet the age range criteria.

The final sample group was of 586 teenagers between 11 and 18 years old (336 females, 248 males and 2 gender not disclosed) of which 50.9% (N= 298) were part of the research group and 49.1% (N= 288) were part of the control group.

The research has also involved the children's parents to complete self and proxy questionnaires, therefore a sample of 937 adults (567 mothers, 370 fathers; Mage= 47,01, SD= 5, 53, with a range between 31 and 63 years old). In this sample 52% (N=283) are the parents of experimental group and 48% (N= 261) are the parents of the control group. In detail, 31,7% (N= 297) are the mothers of the research group and 28,8% (N= 270) are the mothers of the control group, whereas 20,4% (N= 191) are the fathers in the research group and 19.1% (N= 179) are the fathers in the control group. In total there are 60,5% of mothers and 39,5% of fathers.

Table 1

Numerical distribution of participants

	Siblings	Mothers	Fathers	TOT
R. Group	298	297	191	786
C. Group	288	270	179	737
TOT	586	567	370	1523

Focusing on the teenagers' group, the age range was, as expected, between 11 and 18 (M_{age}= 14,49, SD= 2,27). Looking into gender distribution, it is possible to find a fairly homogeneous distribution in both groups with 57,5% of females (N= 336) of which 29,1%, of the research group and 28,4% of the control group and 42,5% of males (N= 248) of which 21,9% of the research group and 20,5% of the control group. For what concerns birth order, the majority of the participants were older than their sibling (N=308), which accounts for the 54,2% of participants compared to the 40,5% of participants who were younger than their siblings (N=230). Interestingly, in the sample there were also 6 participants who were twins, 3 being part of the research group and 3 of the control group. The adolescents who participated in the study were recruited from 39 provinces, with the majority of participants coming from Caltanissetta (N= 64), Padova (N= 61), Treviso (N=50), Vicenza (N= 47), Bari (N= 46) and Brescia (N= 46), accounting for the 42,5% of the entire sample.

Lastly, participants of the research group were asked what kind of disability their sibling had (total participants responding N= 293) and as a result 7 main categories were created with the most common answers: Autism (N= 87); Down Syndrome (N=64); physical and motor disability (N= 54); mental retardation (N= 49); physical disability only (N=24); ADHD and hyperactivity (N=7) and Other (N=8).

3.2.2 Measures

The data was collected through two different questionnaires consisting of a set of standardised self-reports and proxy-reports. One questionnaire for the children and the other for their parents. Research and control group had the same questionnaire, with the only difference being that in the research group there were a few specific questions about the disability each family was dealing with.

The scales used for both children and parents' questionnaires are:

- *Strengths and Difficulties Questionnaire* (SDQ; Goodman, 1997)

The Strengths and Difficulties Questionnaire (SDQ) is a screening instrument widely used in both clinical and research settings. It is a 25 items questionnaire, created in the United Kingdom and then translated and used in 40 different countries. It is a proxy instrument used by parents and teachers to evaluate their students and children between 4 and 16 years old. Although it is not a diagnostic instrument, it is a valid test that can be used to gather valuable information regarding the behavioural, emotional and interpersonal profile of young pupils (Marzocchi et al., 2002). There are two other existing versions of the SDQ, one is a proxy-report for evaluating children between 3 and 4 years old and the other is a self-report for young teenagers between 11 and 16 years old. The 25 items investigate 5 behavioural aspects of the child or young adult which are scored according to the 5 subscales present in the questionnaire: *Hyperactivity/inattention* (items: 2, 10, 15, 21, 25)*, Conduct Problem* (items: 5, 7, 12, 18, 22)*, Emotional Symptoms* (items: 3, 8, 13, 16, 24)*, Peer relationships problem* (items: 6, 11, 14, 19, 23) and *Prosocial behaviour* (items= 1, 4, 9, 17, 20). For the first four a high scoring is associated with high discomfort in these domains, whereas for prosocial behaviour high scoring is associated with altruism and positive outcomes. A 3-point Likert scale (0 = "not true", 1 = "partially true" and 2 = "absolutely true") is offered to answer the questions. Overall, the SDQ has good psychometric properties with high levels of internal consistency reliability, factorial structure and test-retest reliability (Stone et al., 2010; Tobia e Marzocchi, 2017).

- *Family Adaptability and Cohesion Evaluation Scales III* (FACES-III; Olson et al., 1985)

The Family Adaptability and Cohesion Evaluation Scales III (FACES-III) is a self-report composed of 20 items, 10 investigating family cohesion and the other 10 exploring family adaptability, two of the three dimensions inspired by the theoretical model *Circumplex Model of Marital and Family Systems.* This model uses these two dimensions to describe family functioning: family cohesion, defined as emotional bond binding family members; and family adaptability referring to the ability to adapt to external or internal events by changing the family structure (Olson, 2000). The third dimension, which is not investigated in this questionnaire, is family communication and it refers to the modality in which family members express their needs as well as the element that allows dynamic movements within the family facilitating the expression of the other two qualities. According to this model, higher levels of cohesion, adaptability and communication are associated with lower family problems (Thomas and Olson, 1993). The questionnaire FACES III is the revised version of FACES e del FACES II (Olson e Wilson, 1982) investigating as the older scales family *Cohesion* (items: 1, 3, 5, 7, 9, 11, 13, 15, 17, 19) and *Adaptability* (items: 2, 4, 6, 8, 10, 12, 14, 16, 18, 20). It differs from the previous versions as it is shorter, and it has tailored items investigating the difference between ideal family (the individual's representations of an ideal family) and real family (how the individual perceives their family) so that inferences can be made regarding the degree of family satisfaction of each family member of the family they belong to. It has a 5-point Likert scale, ranging from 1 to 5 (1 = "false", 2 = "almost false", 3 = "I don't know", 4 = "almost true", 5 = "true"). The sum of raw scores for each item results in a final score of family cohesion and adaptability for different familiar contexts. In Italy, the questionnaire has been validated by Galimberti and Farina (1990).

- *Parental Acceptance-Rejection Questionnaire* (PARQ; Rohner e Khaleque 2005)

The *Parental Acceptance-Rejection Questionnaire* (PARQ) is a self-report originating from the evidenced-based *Parental acceptance-rejection theory* (PARTheory), a socialization theory aiming6 to explain and predict major consequences of parental acceptance and rejection for behavioural, cognitive and emotional development of children and for the personality functioning of them as adults (Rohner, 1984). Therefore, children's perception of interpersonal acceptance (or rejection) is a fundamental element for healthy coping strategies. In addition, the theory suggests that parental acceptance and rejection can be detected in specific behaviours that caregivers enact when interacting with their children therefore the questionnaire investigates children and parents' perception of past and present acceptance or rejection experienced. The PARQ has multiple versions, all having a long-form constituted of 60 items and a short-form, such as the present one, consisting of 24 items. There are two versions for the parents, one investigating their experience as children and their relationship with their parents and the other asking about their behaviours towards their children. In addition, the other two versions are intended for the children, one is for children between 4 and 7 years old and the other from 7 years old upwards. Each version is constituted of 4 subscales: *Warmth/Affection* (items: 1, 3, 9, 12, 17, 19, 22, 24), which if scores are reversed it is named *coldness/lack of affection*; *Hostility/Aggression* (items: 4, 6, 10, 14, 18, 20); *Undifferentiated Rejection* (items: 2, 5, 7, 8, 13, 15, 23), referring to children's feelings that the parent does not love them, appreciate them or care about them; and *Indifference/Neglect* (items: 5, 8, 16, 21; Rohner, Ali, 2020). A 4-point Likert scale is used for the scoring of the questionnaire, ranging from 1 to 4 (4 = almost always true, 3 = sometimes true, 2 = rarely true , 1 = almost never true). A meta-analysis of 51 studies has shown that the PARQ has a good internal reliability and is a good instrument to use in both clinical and international settings (Khaleque and Rohner, 2002).

- *Siblings Inventory of Behavior* (SIB; Schafer e Edergon, 1981)

Il *Siblings Inventory of Behavior* (SIB) is one of the first instruments created with the intent to investigate and compare the quality of siblings' relationship in pairs with or without a disabled child involved. The questionnaire has been changed and revised multi times (Hetherington & Clingempeel,1992; Hetherington et al.,1999). The last version is composed of 32 items assessing one sibling's behaviour toward the other measures 6 dimensions of sibling behaviour: *Empathy/Concern* (items: 1, 7, 13, 23, 25,)*,* *Companionship/Involvement* (items: 1, 9, 11, 15, 18, 20)*; Rivalry* (items: 3, 8, 10, 17, 19, 21, 30)*; Conflict/Aggression* (items: 5, 12, 16, 22, 32); *Avoidance* (items: 6, 14, 24, 26, 31)*; and Teach/Directiveness* (items: 2, 27, 28, 29). The questionnaire is scored on a 5-point Likert scale going from 1 (=Never) to 5 (=Always).

The scales used only in the children's questionnaire is:

- *Youth Self Report* (YSR/11-18; Achenbach e Rescorla, 2001)

The *Youth Self Report* is a 112-item questionnaire investigating adaptive and emotional functioning, internalised and externalised problems and social competence of children and adolescents between 11 and 18 years old. It is a self-report that is part of the multiaxial system of the *Achenbach System of Empirically Based Assesment* (ASEBA). The multiaxial system allows to gather information from multiple sources in order to have a cross-comparison of the results given by multiple instruments. Indeed, different instruments are distributed to children, their parents or their teachers grasping a wider picture of the area of interest. For instance, the YSR questionnaire is specifically designed for children between 11 and 18 years old and it gathers various information about their behaviours and their emotional experience. A 3-point Likert scale allows to score answers, ranging from 0 to 2 (0 = "absent" 1 = "occurs sometimes", 2 = occurs often). It is made of two main sections: the *Competence Scale Scores* (20 items) and the *Syndrome Scale Scores* (112 items) referring to 8 syndromic subscales: *Anxious/Depressed* (items: 14, 29, 30, 31, 32, 33, 35, 45, 50, 52, 71, 91, 112) investigating depressive and anxiety states; *Withdrawn/Depressed* (items: 5, 42, 65, 69, 75, 102, 103, 111), referring to attitudes of isolation and little search for contact with others; *Somatic Complaints* (items: 47, 51, 54, 56a, 56b, 56c, 56d, 56e, 56f, 56g), which includes physical malaise not explained by any other medical condition; *Social Problems* (items: 11, 12, 25 27, 34, 36, 38, 48, 62, 64, 79), investigating difficulties in social interactions; T*hought Problems* (9, 18, 40, 46, 58, 66, 70, 76, 83, 84, 85, 100), referring to problems of bizarre or negative ideations; *Attention Problems* (items: 1, 4, 8, 10, 13, 17, 41, 61, 78), related to attention difficulties such as difficulties in concentrating, being impulsive; *Rule-Breaking Behaviour* (2, 26, 28, 39, 43, 63, 67, 72, 81, 82, 90, 96, 99, 101, 105)*,* which investigates conduct problems; *Aggressive Behavior* (items: 3, 16, 19, 20, 21, 22, 23, 37, 57, 68, 86, 87, 89, 94, 95, 97, 104), investigating behaviors and attitudes characterized by poor control and aggression. These subscales are divided into three conceptual categories, according to their clinical dimension, forming three main syndromic scales: Internalising problems including the scales *Anxious/Depressed, Withdrawn/Depressed*, *Somatic Complaints*; Externalising Problems including the scales *Rule Breaking Behaviour* and *Aggressive Behaviour*; and lastly, the Scale of *Neither Internalizing nor Externalizing Problems* which includes *Social Problems, Thought Problems and Attention Problems* (Ammaniti et al., 2005). The standardized scores and the cut-off scores allow to compare clinical and non-clinical populations with good values of reliability and validity. As several cross-cultural research has demonstrated, the YSR questionnaire reliability goes from a range of .66-.87, therefore going from good to excellent reliability (Janssens and Deboutte, 2008).

The reports used only in the parents' questionnaire were:

- *Child Behavior Checklist* (CBCL/6-18; Achenbach e Rescorla, 2001)

The *Child Behavior Checklist* is a 112-item proxy-report that is part of the multiaxial system of the *Achenbach System of Empirically Based Assesment* (ASEBA). It is the most widely diffused children behavioural scales used internationally for both research and diagnostic purposes. Frigerio and colleagues have validated the Italian version of the CBCL in 2004 (Frigerio et al., 2004). The CBCL is the proxy version of the YSR report completed by parents. A similar version has been created for teacher and it goes with the name of *Teacher Report Form* (TRF). The CBCL is a questionnaire that investigates social competences as well as behavioural problems of individuals between 6 and 18 years old. The structure and the scoring of the scale are the same ones for the YSR scale: 8 subscales investigating different aspects of children behaviours and emotional experiences divided in 3 main conceptual scales. *Internalising problems* investigating *Anxious/Depressed* (items: 14, 29, 30, 31, 32, 33, 35, 45, 50, 52, 71, 91, 112)*, Withdrawn/Depressed* (items: 5, 42, 65, 69, 75, 102, 103, 111, *Somatic Complaints* (items: 47, 51, 54, 56a, 56b, 56c, 56d, 56e, 56f, 56g); *Neither Internalizing nor Externalizing Problems* including the subscales *Social Problems* (items: 11, 12, 25 27, 34, 36, 38, 48, 62, 64, 79), T*hought Problems* (9, 18, 40, 46, 58, 66, 70, 76, 83, 84, 85, 100), *Attention Problems* (items: 1, 4, 8, 10, 13, 17, 41, 61, 78); and *Externalising problems* including *Rule-Breaking Behaviour* (2, 26, 28, 39, 43, 63, 67, 72, 81, 82, 90, 96, 99, 101, 105) and *Aggressive Behavior* (items: 3, 16, 19, 20, 21, 22, 23, 37, 57, 68, 86, 87, 89, 94, 95, 97, 104). The scale is scored with a 3-point Likert scale ranging from 0 = “absent” to 2 = “occurs often”.

- *Questionnaire of Resources and Stress* (QRS; Saviolo, 1999)

The *Questionnaire of Resources and Stress* is a scale investigating the impact that a disability or a chronic illness of a child has on the whole family system. Originally, it was a 52-item scale created by Holroyd in 1974, subsequently modified by Friedrich and collegues in 1983. It was originally organised in 4 main areas: Parent and family problems (stressful aspects of the impact of the child with disability on parents and the wider family), pessimism (parents’ pessimistic beliefs about the child’s future), child characteristics (features of the child that are associated with increased demands on parents), and physical incapacity (the extent to which the child is able to perform a range of typical activities). It has been widely used with parents of children with disabilities and it has a good reliability (Friedrich et al., 1983), with a good factorial structure (Scott et al., 1989). The version used in this study is the 30-item Italian version created in 1999 by

Saviolo and collegues. It is characterised by 3 subscales: *Parent and family problems (*items: 1, 4, 7, 10, 13, 16, 19, 22, 25, 28), *Pessimism* (items: 2, 5, 8, 11, 14, 17, 20, 23, 26, 29)*, and Disabled child characteristics* (items: 3, 6, 9, 12, 15, 18, 21, 24, 27, 30). Each item as a True/False answer choice.

Overall, the scales used for the purpose of this study can be divided in two primary areas of interest: questionnaires investigating social ecological factors (FACES-III, SIB, PARQ, QRS) and questionnaires focusing on individual factors (SDQ, YSR, CBCL).

3.2.3 Procedure

This study is part of a larger research project started a few years ago, therefore the dataset is composed of a large amount of data collected in different Italian regions. Participants have been contacted throughout the years through the help of local associations working with individuals with disabilities and their families, but also through word-of-mouth, social networks and personal acquaintances. In this study specifically, participants of the research group were recruited thanks to the collaboration of the Onlus Roma Cares headquartered in Rome and the Association Vite Vere Down Dadi based in Padua. The Onlus situated in Rome has the primary goal to promote in young individuals with cognitive disabilities positive values and sense of community through sports; whereas the association situated in Padua works with individuals with Down Syndrome, autism and intellectual disability helping them throughout their development to reach an autonomous life in order to live together in small groups independently when older. Both organisations reached out to the families of the disabled children participating in their projects looking to recruit their parents and their siblings who were between 11 and 18 years old. Participants of the control group were subsequently recruited, paring them with the research group according to age, gender and birth order.

Participants were introduced to the research project and were given a participant information sheet before signing the consent form and filling out the questionnaire. The participant information sheet consisted of a small explanation of the research conducted, the main aims and goals of the study, a summary of the research methodology and the type of information the scales would evolve around. It also gave an average duration time to fill out the questionnaire and provided numbers and email addresses of the responsible of the research. In addition, it presented information about the anonymity of the data collected, the privacy policy and data treatment, referring to the related laws. Participants were reminded that the participation to the study was voluntary and they could withdraw their participation to the study at any time during their compilation of the questionnaire or later on without giving any explanations about it, and lastly if they wished to, they could ask for a restitution of their raw data. Both parents and their young children had to sign the content form regardless of their age to participate in the study. After reassuring people of the possibility to ask questions at any time during or after the compilation, questionnaires were handed to them. However, since the pandemic caused by COVID-19 from 2020 questionnaires have also been transformed into an online version of Google Forms and sent online. Since then, modality of administration of the questionnaires has been either online or in person for both groups.

Questionnaires for parents and children were diversified, with parents having a few personal and demographic questions to cover and then answer questions about their children participating in the research – hence the sibling of a disabled child – through proxy-reports. On the other hand children's questionnaires were self-reports asking about their thoughts, their behaviours, their performance at school, and their relationship with their parents and sibling. In order to match the pair of siblings in the two groups, the participants of the research group had to think about their relationship with their disabled sibling, whereas the control group had to think about the sibling that matched at best the birth order, age and gender of the disabled individual of the pairs in the research groups. Pairs were carefully matched beforehand by the responsible of the study to ensure that a balance sample would be created.

Both research and control groups had the same questionnaires with the only exception being two questions for the research group in which it was asked what kind of disability their sibling had and child and how satisfied parents were with the services offered to support the disability of their child.

Once questionnaires were completed, it was possible to score them and add them up to the existing datasets in Excel produced over the years. Lastly, the parents and siblings’ datasets were imported on SPSS to be analysed in order to answer the research questions of this specific study.

3.3 Results

In order to explore differences between research and control group on relevant emotional, behavioural and social functioning, it was analysed the difference in scoring through a *t-test* on the YSR (investigating depressive mood, withdrawal, somatic complaints, thought problems, attention problems, rule-breaking behaviour, aggressive behaviour), the SDQ (exploring the trends for what concerns hyperactivity, conduct problems, emotional symptoms, peer relationship problems and prosocial behaviour), and the CBCL (investigating the same problems found in the YSR but through the perspective of the parents). In order to check the homoscedasticity, or homogeneity of variances, a Levene's test was run for all subscales showing that most variances were not significantly different, thus the homogeneity assumption was met.

3.3.1 t-tests and Descriptive Statistics

Youth Self Report analyses

The means, standard deviations and internal reliabilities (Cronbach’s alpha coefficient) of each YSR subscales are reported in Table 2 below.

Table 2

Means, standard deviations, internal reliabilities of YSR completed by siblings

	YSR-SIBLINGS					
	R. Group			**C. Group**		
Subscales	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Anxious/Depressed (α= .80)	297	6,13	4,46	288	5,88	3,99
Withdrawn/Depressed (α= .76)	297	3,43	3,03	288	2,80	2,55
Somatic Complains (α= .73)	297	4,02	3,29	288	3,46	2,80
Social Problems (α= .66)	297	3,60	2,97	288	3,31	2,63
Thoughts Problems (α= .64)	297	7,78	3,65	288	7,32	3,31
Attention Problems (α= .68)	297	5,94	3,22	288	5,60	3,17
Rule-Breaking Behaviour (α= .54)	297	5,59	2,77	288	4,91	2,77
Aggressive Behaviour (α= .71)	297	8,31	4,07	288	7,37	3,73
Internalising Problems (α= .88)	297	13,57	9,24	288	12,07	7,71
Externalising Problems (α= .77)	297	13,90	6,08	288	12,28	5,65
TOT Problems (α= .93)	297	44,78	21,19	288	40,57	18,16

In order to look at relevant differences between means on the YSR between groups, a *t-test* was carried out (Table 3) which found a significant difference between groups in the dimensions: Withdrawn/Depressed (t= 2,72), Somatic Complains (t= 2,21), Rule-breaking Behaviour (t= 2,98) and Aggressive Behaviour (t= 2,90) with the research group scoring significantly higher on these problems compared to the control group. Overall, the research group scored significantly higher in both externalising and internalising problems suggesting that young teenagers of this group were dealing with more problems compared with peers of the control group.

Table 3

t-test YSR sibling

	YSR - SIBLINGS		
Subscales	**t**	**gl**	**Sign. (two-tailed)**
Anxious/Depressed	0,90	579,26	0,37
Withdrawn/Depressed	2,72	571,67	0,01**
Somatic Complains	2,21	573,19	0,03*
Social Problems	1,26	578,49	0,21
Thoughts Problems	1,61	580,51	0,11
Attention Problems	1,32	583	0,19
Rule-Breaking Behaviour	2,98	583	0,001***
Aggressive Behaviour	2,90	583	0,001***
Internalising Problems	2,13	570,44	0,03*
Externalising Problems	3,33	583	0,001***
TOT Problems	2,59	574,41	0,01***

* p-value ≤ 0,05; ** p-value ≤ 0,01; *** p-value ≤ 0,001

Child Behavior Checklist analyses

The means, standard deviations and internal reliabilities (Cronbach's alpha coefficient) of each CBCL subscales are reported in Table 4 (CBCL mothers) and Table 5 (CBCL fathers) below.

Table 4

Means, standard deviations, internal reliabilities of CBCL completed by mothers

	CBCL-MOTHERS					
	R. Group			**C. Group**		
Subscales	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Anxious/Depressed (α= .77)	292	4,29	3,47	269	3,31	2,92
Withdrawn/Depressed (α= .70)	292	2,62	2,62	269	1,69	1,75
Somatic Complains (α= .69)	292	1,98	2,47	269	1,32	1,81
Social Problems (α= .74)	292	3,07	3,23	269	1,53	1,72
Thoughts Problems (α= .70)	292	2,17	2,77	269	1,05	1,45
Attention Problems (α= .78)	292	4,31	3,85	269	2,75	2,50
Rule-Breaking Behaviour (α= .64)	292	2,10	2,34	269	1,41	1,59
Aggressive Behaviour (α= .80)	292	4,69	4,23	269	3,41	2,90
Internalising Problems (α= .86)	292	8,89	6,96	269	6,34	5,13
Externalising Problems (α= .84)	292	6,80	5,96	269	4,82	3,97
TOT Problems (α= .94)	292	25,18	19,49	269	16,49	11,75

Table 5

Means, standard deviations, internal reliabilities of CBCL completed by fathers

	CBCL-FATHERS					
	R. Group			C. Group		
Subscales	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Anxious/Depressed (α= .77)	177	3,51	3,58	172	3,03	2,96
Withdrawn/Depressed (α= .70)	177	2,28	2,44	172	1,57	1,72
Somatic Complains (α= .69)	177	1,69	2,45	172	1,19	1,71
Social Problems (α= .74)	177	2,45	3,04	173	1,41	1,70
Thoughts Problems (α= .70)	177	1,59	2,52	172	1,01	1,53
Attention Problems (α= .78)	177	3,80	3,72	179	2,71	2,58
Rule-Breaking Behaviour (α= .64)	188	1,88	2,72	179	1,33	1,86
Aggressive Behaviour (α= .80)	177	4,15	4,46	172	3,12	2,77
Internalising Problems (α= .86)	177	7,47	7,30	172	5,80	5,01
Externalising Problems (α= .84)	188	5,89	6,74	179	4,43	4,35
TOT Problems (α= .94)	188	22,17	22,05	179	15,60	12,36

A t- test was carried out to analyse significant differences between means of the CBCL completed by mothers (Table 6) resulting in a significant difference in all subscales, with the research group scoring significantly higher than the control group: Anxious/Depressed (t= 3,60); Withdrawn (t= 4,97); Somatic Complains (t= 3,66); Social Problems (t= 7,12); Thoughts Problems (t= , 6,04); Attention Problems (t= 5,74; Rule-Breaking Behaviour (t= 4,12); Aggressive Behaviour (t= , 4,22); Internalising Problems (t= 4,98); Externalising Problems (t= 4,66).

Furthermore, a t- test was carried out to analyse significant differences between means of the CBCL completed by father (Table 7) resulting in a significant difference in all the subscales apart from Anxious/Depressed, with the research group scoring significantly higher than the control group: Withdrawn (t= 3,16); Somatic Complains (t= 2,20); Social Problems (t= 3,95); Thoughts Problems (t= 2,56); Attention Problems (t= 3,26); Rule-Breaking Behaviour (t= 2,26); Aggressive Behaviour (t= 2,60); Internalising Problems (t= 2,50); Externalising Problems (t= 2,47).

Table 6

t-test CBCL mothers

	CBCL - MOTHERS		
Subscales	**t**	**gl**	**Sign. (two-tailed)**
Anxious/Depressed	3,60	554,64	0,001***
Withdrawn/Depressed	4,97	511,19	0,001***
Somatic Complains	3,66	532,66	0,001***
Social Problems	7,12	451,78	0,001***
Thoughts Problems	6,04	446,34	0,001***
Attention Problems	5,74	503,66	0,001***
Rule-Breaking Behaviour	4,12	514,63	0,001***
Aggressive Behaviour	4,22	517,28	0,001***
Internalising Problems	4,98	533,77	0,001***
Externalising Problems	4,66	510,24	0,001***
TOT Problems	6,46	484,00	0,001***
* p-value ≤ 0,05; ** p-value ≤ 0,01; *** p-value ≤ 0,001			

Table 7

t-test CBCL fathers

	CBCL - FATHERS		
Subscales	**t**	**gl**	**Sign. (two-tailed)**
Anxious/Depressed	1,35	347	0,18
Withdrawn/Depressed	3,16	317,02	0,001***
Somatic Complains	2,20	314,86	0,029*
Social Problems	3,95	277,63	0,001***
Thoughts Problems	2,56	291,68	0,01**
Attention Problems	3,26	331,85	0,001***
Rule-Breaking Behaviour	2,26	331,41	0,01**
Aggressive Behaviour	2,60	295,61	0,01**
Internalising Problems	2,50	312,31	0,01**
Externalising Problems	2,47	321,87	0,01**
TOT Problems	3,54	296,86	0,001***

* p-value ≤ 0,05; ** p-value ≤ 0,01; *** p-value ≤ 0,001

Strengths and Difficulties Questionnaire analyses

The means, standard deviations and internal reliabilities (Cronbach's alpha coefficient) of each SDQ subscales are reported in Table 8 (siblings), Table 10 (mothers) and Table 12 (fathers).

Table 8

Means, standard deviations, internal reliabilities of SDQ completed by siblings

	SDQ-SIBLINGS					
	R. Group			**C. Group**		
Subscales	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Hyperactivity/inattention (α= .71)	291	2,74	2,19	288	2,78	2,03
Conduct problems (α= .49)	291	1,71	1,50	288	1,41	1,29
Emotional symptoms (α= .70)	291	2,68	2,19	288	2,19	1,94
Prosocial behaviour (α= .67)	291	7,74	1,75	288	7,76	1,75
Peer relationships problem (α= .59)	291	1,75	1,72	288	1,60	1,70
TOT problems (α= .81)	291	8,87	5,66	288	7,98	4,96

In order to look at relevant differences between means on the SDQ completed by siblings between groups, a *t-test* was carried out (Table 9) which found a significant difference between groups in conduct problems (t= 2,52) and emotional problems (t= 2,75) with the research group scoring significantly higher on these problems compared to the control group suggesting, as expected, that siblings of children with a disability deal with more problems compared with peers of the control group.

Table 9

t-test SDQ sibling

	SDQ -SIBLINGS		
Subscales	**t**	**gl**	**Sign. (two-tailed)**
Hyperactivity/inattention	-0,27	577	0,79
Conduct problems	2,52	565,75	0,01**
Emotional symptoms	2,75	558,32	0,001***
Prosocial behaviour	-0,13	569,68	0,90
Peer relationships problems	1,09	577	0,28
TOT problems	2,01	577	0,05*

* p-value ≤ 0,05; ** p-value ≤ 0,01; *** p-value ≤ 0,001

Table 10

Means, standard deviations, internal reliabilities of SDQ completed by mothers

	SDQ - MOTHERS					
	R. Group			**C. Group**		
Subscales	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Hyperactivity/inattention (α= .69)	292	2,54	2,24	268	1,68	1,68
Conduct problems (α= .46)	291	1,50	1,52	268	1,10	1,13
Emotional symptoms (α= .66)	292	2,11	2,16	268	1,30	1,42
Prosocial behaviour (α= .65)	291	7,71	2,06	268	7,93	1,90
Peer relationships problem (α= .62)	292	2,24	2,14	268	1,14	1,32

In order to look at relevant differences between means on the SDQ completed by mothers between groups, a *t-test* was carried out (Table 11) which found a significant difference between groups in the following subscales: The Hyperactivity/inattention (t= 5,17); Conduct problems (t= 3,59); Emotional symptoms (t= 5,28); Peer relationships problems (t=7,39), with the research group scoring higher than the control group in all scales.

Table 11

t-test SDQ mothers

	SDQ -MOTHERS		
Subscales	**t**	**gl**	**Sign. (two-tailed)**
Hyperactivity/inattention	5,17	536,80	0,001***
Conduct problems	3,59	533,52	0,001***
Emotional symptoms	5,28	507,74	0,001***
Prosocial behaviour	-1,32	577	0,19
Peer relationships problems	7,39	489,99	0,001***
* p-value ≤ 0,05 ; ** p-value ≤ 0,01; *** p-value ≤ 0,001			

Table 12

Means, standard deviations, internal reliabilities of SDQ completed by fathers

	SDQ - FATHERS					
	R. Group			**C. Group**		
Subscales	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Hyperactivity/inattention (α= .69)	177	2,10	1,81	172	1,65	1,68
Conduct problems (α= .46)	177	1,26	1,406	172	1,01	1,07
Emotional symptoms (α= .66)	177	1,63	1,70	172	1,17	1,34
Prosocial behaviour (α= .65)	177	7,70	2,05	172	8,23	1,57
Peer relationships problem (α= .62)	177	1,77	1,88	172	1,02	1,20

In order to explore relevant differences between means on the SDQ completed by fathers between groups, a *t-test* was carried out (Table 13) which found a significant difference between groups all subscales: The Hyperactivity/inattention (t= 2,42); Conduct problems (t= 1,93); Emotional symptoms (t= 2,82); Prosocial behaviour (t= -2,70); Peer relationships problems (t= 4,44), with the research group scoring higher than the control group in all scales apart from the Prosocial behaviour scale in which the fathers of the control group scored higher, meaning that their children were judged by having a more prosocial behaviour compared to how the parents of the research group judged their children.

Table 13

t-test SDQ fathers

	SDQ -FATHERS		
Subscales	**t**	**gl**	**Sign.** **(two-tailed)**
Hyperactivity/inattention	2,42	347	0,02*
Conduct problems	1,93	328,73	0,5*
Emotional symptoms	2,82	333,38	0,01**
Prosocial behaviour	-2,70	328,86	0,01**
Peer relationships problem	4,44	300,49	0,001***

* p-value ≤ 0,05; ** p-value ≤ 0,01; *** p-value ≤ 0,001

3.3.2 Correlational Analyses and Descriptive Statistics

Moving on the second research question, correlational analyses were carried out to analyse the quality of the relationship between siblings and examine whether in the research group the fraternal relationship is influenced by the disability of one of the two, correlating in low scoring of other dimensions representative of family dynamics. Results were compared with the control group, which is not characterised by a member with a disability.

The analyses focused on correlation between the *Sibling Inventory of Behaviour,* measuring the quality of fraternal relationship, and other three scales: the *Family*

Adaptability and Cohesion Evaluation Scales III (FACES III), which gives an understanding on the cohesion and adaptability of the family; the *Parental Acceptance-Rejection Questionnaire* (PARQ), investigating the perception that children have on whether they are accepted or rejected by their parents.

All means, standard deviations and internal reliabilities of the SIB (Table 14), FACES III (Table 15), PARQ mothers (Table 16), PARQ fathers (Table 17) completed by siblings of research and control group are consultable below.

Table 14

Means, standard deviations, internal reliabilities of SIB completed by siblings of research and control group

	SIB - SIBLINGS					
	R. Group			**C. Group**		
Subscales	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Companionship (α = .80)	292	19,01	5,35	288	20,88	5,02
Empathy (α = .81)	292	19,71	4,42	288	19,45	4,68
Teach (α = .84)	292	13,87	4,22	288	12,69	4,47
Rivalry (α = .61)	292	12,71	3,99	288	14,34	4,21
Conflict (α = .78)	292	8,99	3,23	288	11,06	3,63
Avoidance (α = .78)	292	7,03	3,02	288	6,49	2,53

Table 15

Means, standard deviations, internal reliabilities of FACES III completed by siblings of research and control group

	FACES III - SIBLINGS					
	R. Group			**C. Group**		
Subscales	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Cohesion (α = .87)	291	39,32	7,84	288	39,59	7,38
Adaptability (α = .63)	291	30,44	6,47	288	29, 02	5, 60

Table 16

Means, standard deviations, internal reliabilities of PARQ about mothers completed by siblings of research and control group

	PARQ -MOTHERS					
	R. Group			**C. Group**		
Subscales	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Warmth/Affection (α = .91)	292	5,08	5,64	288	5,73	6,03
Undifferentiated rejection (α= .88)	292	16,89	4,62	288	16,92	4,98
Hostility/Aggression (α = .85)	292	14,53	3,80	288	14,34	4,18
Indifference/Neglect (α = .82)	292	10,19	2,76	288	10,04	3,01

Table 17

Means, standard deviations, internal reliabilities of PARQ about fathers completed by siblings of research and control group

	PARQ -FATHERS					
	R. Group			C. Group		
Subscales	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Warmth/Affection (α = .90)	292	7,14	5,95	285	7,75	5,88
Undifferentiated rejection (α= .86)	292	16,00	4,73	285	15,26	5,22
Hostility/Aggression (α = .83)	292	14,11	3,88	285	14,09	4,19
Indifference/Neglect (α = .83)	290	9,87	2,88	285	9,78	3,19

In both groups all SIB subscales, apart from one in the research group, significantly correlated with the subscales of FACES III, family Cohesion and Adaptability (Table 18). The correlations went from weak to moderate. In the research group, cohesion had the strongest positive correlation with Companionship (r= .44). It also had a positive correlation with Empathy (r= .39) and Teach (.35). On the other hand, it negatively correlated with Avoidance (r= -.36), Conflict (r= -.26) and Rivalry (r= -.19). Adaptability correlated in the same direction as Cohesion did with all subscales, apart from Rivalry, but correlations were less strong. In other words, when *siblings* had a positive relationship with their disabled brother or sister, they also had a better cohesion and adaptability with their family. In the control group (Table 18), a similar trend was found, the direction of the correlations was the same as the research group, however most SIB subscales correlated more strongly with Cohesion and Adaptability compared to the research group.

Table 18

Means, SD of subscales and Pearson's correlation between SIB and FACES III completed by siblings of research and control group

		RESEARCH G.					
		SIB					
		Companionship	Empathy	Teach	Rivalry	Conflict	Avoidance
FACES III	Cohesion	,44**	,39**	,35**	-,19**	-,26**	-36**
	Adaptability	,28**	,20**	,25**	-,01	-,16**	-,14*
		CONTROL G.					
		SIB					
		Companionship	Empathy	Teach	Rivalry	Conflict	Avoidance
FACES III	Cohesion	,55**	,50**	,38**	-,16**	-,37**	-,35**
	Adaptability	,33**	,23**	,23**	-,12*	-,25**	-,19**

* p-value ≤ 0,05; ** p-value ≤ 0,01; *** p-value ≤ 0,001

For what concerns the correlation between SIB and PARQ completed by siblings of the research group (Table 19), the correlations were mostly significant but weak. Subscales of PARQ mothers correlated half of the time positively and half negatively. The subscale Warmth correlated negatively with Companionship (r= -.30), Empathy (-.30) and Teach (-.28) and positively with Conflict (.16) and Avoidance (.23). The opposite trend was visible for Rejection, Hostility and Neglect which positively correlated with Companionship, Empathy and Teach, and negatively correlated with Rivalry, Conflict and Avoidance. The was no significant correlation between Rivalry and Warmth and Conflict and Neglect. A similar trend was visible for subscales of PARQ fathers, with the strongest positive correlation between Teach and Rejection (r= .24) and the strongest negative correlation between Rivalry and Aggression (r= -.28). Neglect and Hostility were not significantly correlated with Companionship. In other words, when siblings of the research group negatively perceived the way their mothers and fathers treated them, they had a better relationship with their disabled sibling.

On the other hand, for what concerns the correlation between SIB and PARQ completed by siblings of the control group (Table 19), the direction of the correlations and their strength was the same found in the research group; nevertheless, most subscales did not significantly correlate with each other, especially SIB with PARQ mothers. Specifically, in PARQ mothers, Affection correlated negatively with Companionship (r= -.20), Empathy (r= -.16) and Teach (r= -.15); and Rejection correlated positively with Companionship (r= .18), Empathy (r= .14) and negatively with Avoidance (r= -.16). In PARQ fathers, Rejection correlated with all SIB dimensions, with the strongest correlation being with Avoidance (r= -.28). Warmth correlated with all SIB subscales apart from Rivalry, and it had the strongest correlation with Companionship (r= -.34). Hostility and Neglect did not significantly correlate with most SIB subscales apart from Companionship (r=. 21), Avoidance (respectively r= -.19; r= -.22) and Empathy but only with Neglect (r=. 12). To sum up, the analysis did not find relevant correlations between how siblings of the control group perceived their mothers' attitudes and how they interacted with their brother or sister. When a correlation was found, it was weak and went in the same direction as it did in the research group. There were more correlations between how they perceived their fathers' behaviours and their relationship with their brother or sister, but it was also weak and went in the same direction of the research group, meaning that negative perception of their parents' behaviours was linked to a better relationship with their siblings.

Table 19

Pearson's correlation between SIB and PARQ completed by siblings of research and control group

RESEARCH G.							
		SIB					
		Companionship	**Empathy**	**Teach**	**Rivalry**	**Conflict**	**Avoidance**
PARQ MOTHERS	**Warmth/Affection**	**-,30****	**-,30****	**-,28****	,10	**,16****	**,23****
	Undifferentiated rejection	**,19****	**,23****	**,20****	**-,16****	**-,13***	**-,21****
	Hostility/Aggression	**,12***	**,21****	**,17****	**-,23****	**-,13***	**-,20****
	Indifference/Neglect	**,12***	**,19****	**,18****	**-,15****	-,10	**-,18****
PARQ FATHERS	**Warmth/Affection**	**-,24****	**-,25****	**-,23****	**,13***	**,23****	**,16****
	Undifferentiated rejection	**,19****	**,23****	**,24****	**-,19****	**-,19****	**-,22****
	Hostility/Aggression	,08	**,15****	**,12***	**-,28****	**-,18****	**-,20****
	Indifference/Neglect	,11	**,15***	**,16****	**-,22****	**-,14***	**-,19****
CONTROL G.							
		SIB					
		Companionship	**Empathy**	**Teach**	**Rivalry**	**Conflict**	**Avoidance**
PARQ MOTHERS	**Warmth/Affection**	**-,20****	**-,16****	**-,15****	-,04	,03	,12
	Undifferentiated rejection	**,18****	**,14***	,09	-,04	-,08	**-,16****
	Hostility/Aggression	,11	-,01	,04	,01	-,03	-,05
	Indifference/Neglect	,10	,11	,04	-,02	-,05	-,09

PARQ FATHERS	**Warmth/Affection**	**-,34****	**-,21****	**-,19****	,04	**,15****	**,24****
	Undifferentiated rejection	**,27****	**,13***	**,13***	**-,13***	**-,16****	**-,28****
	Hostility/Aggression	**,21****	,07	,09	-,09	-,11	**-,19****
	Indifference/Neglect	**,21****	**,12***	,10	-,07	-,08	**-,22****

* p-value ≤ 0,05 ; ** p-value ≤ 0,01; *** p-value ≤ 0,001

4.1 Discussion

Multiple instruments have been adopted to analyse in depth *siblings* experience comparing it with the experience of peers who do not have a brother or a sister with a disability. The first research question was interested to verify if a child disability does affect their sibling, looking if there are trajectories towards relevant psychopathological disorders as well as maladaptive behaviours and social difficulties comparing the results with a control group. It was hypothesised that siblings of the research group, hence children with a brother or sister with a disability, would have more psychopathological difficulties, maladaptive behaviours and social problems compared to the control group.

A t-test was run in order to look at differences in scoring between groups in the Youth Self Report (YSR). The results showed that there was a significant difference between the two groups in Withdrawal, Somatic complains, Rule-Breaking Behaviour and Aggressive Behaviour with the research group of *silbings* experiencing more symptoms related to these problems compared to the control group. Overall, the research group suffered more of both internalising and externalising symptoms compared to the control group. These findings are in line with previous literature showing how siblings of disabled children show more psychological, social and behavioural problems compared to peers of their age (Caliendo et al., 2020).

Furthermore, a t-test was run in order to look at differences in scoring between parents of both groups in the CBCL (investigating the same problems found in the YSR but through the perspective of the parents). According to the parents prospective, children of the research group experienced significantly more problems compared to their peers of the control group in all dimensions investigated by the questionnaire. Hence, both mothers and fathers of the research group agreed that their children had more symptoms and behaviours linked with somatic complains, social problems, thought problems, attention problems, rule-breaking and aggressive behaviours. The only difference between mothers and fathers' perspective was on anxiety and depression, as the mothers of the research group highlighted significantly more problems than the mothers of the control group did; whereas fathers of the research group reported just a few more depressive and anxiety symptoms compared to the fathers of the control group. Overall, mothers and fathers of the research group reported significantly more problems in both internalising and externalising areas of their children functioning, implying that, even if they deal with the disability of a child, it does not mean they do not see the evident problems their other children are facing.

Comparing the means of the questionnaires completed by siblings of both groups with the means of the questionnaires completed by their parents it is evident how children have scored higher in all problems compared to their parents. For instance, both mothers and fathers of research and control group have similarly reported that their children had less behavioural, social and emotional problems compared to what their children have reported. This underestimation was more evident in fathers, although their scoring was similar to the ones of the mothers. If going through adolescence is difficult for children in a typical family underestimating their feelings and problems, it is only possible to imagine what implications this has for children whose needs cannot be properly addressed due to the issues of their siblings with a disability or pathology, which shadow necessarily the problems and needs of these "invisible children", which develop feelings of neglect (Von der Dunk 1983).

Lastly, a t-test was run in order to look at differences in scoring between siblings and parents of both groups in the SDQ (exploring the trends for what concerns hyperactivity, conduct problems, emotional symptoms, peer relationship problems and prosocial behaviour). The analysis found a significant difference between groups according to both children and parents' perspectives. The children of the research group reporting significantly more issues in the conduct and emotional problems. Their mothers reporting that their children had significantly more problems with hyperactivity, conducts, emotional symptoms and peer relationships compared to what reported by the mothers of the control group. Their fathers reported more problems in all dimensions of the SDQ. Interestingly, both mothers and fathers of the research group reported less prosocial behaviours of their children compared to the prosocial behaviour highlighted by parents of the control group, however there was only a significant difference between the father groups. This could be due to the fact that parents who have a disabled child unconsciously expect from their healthy child more empathetic maturity considering they expect them to care for their sibling (McHale & Gamble, 1989) and hope that when their children will be older, their typically developed child will care for their brother or sister with difficulties (Hatfield, & Lefley, 2005). In other words, they may expect their children to have stronger prosocial behaviours so that in the future they can take their place as caregivers, often forgetting that their children are just children, and they need time to mature and develop their assets to the fullest.

Overall, this first part of analyses suggested that as the first hypothesis stated children with a disabled brother or sister experience more psychological, behavioural and social problems compared to their peers who do not have a sibling with a disability.

The second research question was interested in verifying if a child who has a sibling with a disability experiences less relational issues with their disabled sibling compared to their peers, as recent literature showed an interesting trend according to which families dealing with a disability and who learn to be resilient form more meaningful bonds between siblings and maintain them throughout all the lifespan (Burbidge & Minnes, 2014). Also, this analysis was interested in looking if their relationship correlated positively or negatively with how children were treated by their parents and by the family cohesion and adaptability.

In order to analyse this research question, a first correlational analysis between the questionnaire SIB, measuring the quality of fraternal relationship, and FACES, giving information about cohesion and adaptability of a family. The analysis showed that there were no substantial differences between groups. In the research group Cohesion had the strongest positive correlation with Companionship. It also had a positive correlation with Empathy and Teach, meaning that when family cohesion was high, siblings of disabled children would spend time with them, were more empathic towards them and would spend time teaching their sibling skills. On the other hand, it negatively correlated with Avoidance, Conflict and Rivalry. Hence when family cohesion was high there were little rivalry, conflict and avoidance in the fraternal relationship. Adaptability correlated in the same direction as Cohesion did with all subscales, but it did not correlate with Rivalry. Correlations were overall less strong. In the control group, a similar trend was found, the direction of the correlations was the same as the research group, however most SIB subscales correlated more strongly with Cohesion and Adaptability compared to the research group. Therefore, in both groups a common trend was found: when there was a good cohesion and adaptability within the family, siblings of research and control group had a positive relationship with their brother or sister regardless the fact they were disabled or not. Overall, this research has highlighted a good level of family cohesion and adaptability of families with a disabled child, which however did not significantly differ by the experience of typically developed families. Both groups had indeed the same level of cohesion and adaptability and these similarly correlated with the fraternal relationship of children of both groups. Therefore, this research has not found an outstanding result in terms of family positive outcomes related to having a child who has a form of disability, pathology, or syndrome. Perhaps, there are long-term positive aspects more visible when *siblings* get older (Rossiter & Sharpe, 2001), such as greater empathy and more appreciation for people with disabilities (Grossman,1972). However, what is arguable is that regardless the family situation, hence with or without challenges that come with a disability of a child, cohesion and adaptability are important factors determining a good relationship between siblings.

A second correlational analysis was run between the questionnaire SIB and the questionnaire PARQ, investigating how children perceive how they parents treat them and care for them. Overall, the relationship of the research group with their disabled brother or sister correlated with many dimensions related to how they perceived their parents treating them. In detail, the correlation of SIB with PARQ mothers showed negative correlations between the dimension Warmth/Affection with Companionship, Empathy, and Teach and positive correlations with Conflict and Avoidance. The opposite trend was visible for Rejection, Hostility and Neglect which positively correlated with Companionship, Empathy and Teach, and negatively correlated with Rivalry, Conflict and Avoidance. A similar trend was visible for subscales of PARQ fathers, with the strongest positive correlation between Teach and Rejection and the strongest negative correlation between Rivalry and Aggression. A similar trend was found in the control group with the substantial difference that although correlations pointed towards the same directions, just few of them were significant, especially in the analysis focusing on the mothers' attitudes. What is interesting to notice in both groups, with stronger implications for the research group as most correlations were significant, it is an expected trend showing that when children perceived their parents' actions as more hostile, neglectful, and felt more rejected, they had a more positive relationship with their siblings. Whereas, when they perceived their parents as more affectionate, they had - paradoxically - a worse relationship with their sibling. These results are not in line with previous research as studies have been found that a good relationship between child and parent and high levels of affection and warmth are positively associated with a good fraternal relationship (Brody al., 1994). The findings of this present study could signify, perhaps, that when parents do not adapt functionally to the challenges of life, especially families dealing with a disability, they could place their frustration and distress in their relationship with their children, treating them with hostility and neglecting their needs, resulting in a stronger bond between siblings who in order to "survive" to the hostile environment in which they are growing, they take care of each other. Whereas, when parents fulfil their parental duties, children do not need to rely on their siblings as much and therefore their relationship is less solid and more typical for their developmental stage, as during adolescence it is normal for children to experience conflictual relationships with their siblings (Scharf et al., 2005). Another possible explanation of this finding is that as participants of the study are teenagers between 11 and 18 years old, considering that this stage of life is characterised by a conflictual relationship with parents, need of independence and teenagers go through a separation process which contributes to the creation of their own identity, perhaps participants' judgment is the result of these specific developmental tasks.

4.2 Limitations and Future Directions

This section will outline some of the limitations of this study in order to allow future research to overcome them and produce more reliable findings within this area. First of all, this research has not focused on the impact of psychosocial factors of a family unit such as economic stability, social economic status (SES), social support, cost of care depending on region, and the perception of the society towards disability. Considering literature has highlighted the impact of these factors on the way families adapts to the challenges of dealing with a disability or pathology of a child, future research needs to control for these variables in order to see if there are significant differences between families with different economical resources and a different social support. In addition, the study failed to find higher prosocial behaviours of the research group compared to control group. Considering that some articles have found that birth order and age spacing are important discriminants when looking at children's psychological developmental as well as their behaviours towards their disabled brother or sister (Dallas et al., 1993), future studies should perhaps control for this variable in a regression analysis in order to look how much it impacts on the relationship between prosocial behaviour and having a brother or sister with a disability. A longitudinal study could compare how new generations experience disability compared to older generations and if society perceptions and social support are discriminatory variables in a possible generational difference. In addition, considering the unexpected direction of the results regarding the correlation between how children perceive their parents' actions as more hostile, neglectful, and felt more rejected, and the stronger relationship with their siblings, future research should look at the differences in how parents treat both of their children, the typical developed child and the disabled child and their possible lack of care for both children. If research finds if that children who have a better relationship are treated in a similar way, this relationship could be explained by lack of adequate care, as mentioned in the previous section. However, if children receive a differential treatment, then there may be other underlying reasons why this trend is manifested. Lastly, future studies should analyse more in details the kind of disability the disabled child has, its severeness and its impact on everyday functioning in order to better discriminate what may affect the relationship with their siblings and find out which pathologies and disabilities have a greater impact to the well-being of their families and in particular of their siblings.

CONCLUSION

This research suggests taking a holistic approach on disability by looking at the full picture of children who have a disabled brother or sister instead of declining the experience as being mostly positive or negative. Indeed, as positive and negative factors coexist in typically developed families, the same happens in families characterised by the disability of a child (Summers et al., 1994; Fisman et al., 2000). They are two sides of the same coin. Hoping to reach a perfect scenario in which families manage everything functionally, there are no issues, psychological distress is utopistic. This does not discredit the fact that social and psychological support for siblings is needed. On the contrary, these children need to be supported in order to reduce as much as possible negative outcomes, focusing on the positive resources found within the family, their cohesion, their empathy. Enhancing their resilience and functional coping mechanisms whist reducing their negative cognitions. In this way, disability can turn from being a simple obstacle to what was planned as a wonderful journey for all family members. This study analysed the experience of siblings between 11 and 18 years old through the use of self and proxy reports and used t-tests to look at the well-being and difficulties of the research and control group and used Pearson's correlation coefficients to look at the association of the fraternal bond with some family characteristics, such as family cohesion and adaptability and parental affection-rejection. The results of this study supported a multi-faced experience, that is characterised by having apparent difficulties - such as somatic complains, withdrawal, conduct problems and peer relationship problems - compared to peers without a disabled brother or sister, while having enhanced intrinsic resources, such as a stronger family cohesion and a stronger fraternal bond with the disabled child. Future studies should look at whether an association exists between a strong bond between siblings and higher levels of rejections for both healthy and disabled children as a result of a lower parental adaptation to the disability of the child.

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