

# Being Parents of Sons with Disabilities: A Qualitative Analysis of Personal Perceptions and Service Experience

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*Abstract.* Although parents could encounter both negative and positive aspects in parenting a son with disabilities, many studies have been primarily focused on the negative aspects that increase parents' stress level and on the factors that can reduce this level, such as social and formal support. This study aims to investigate how these parents perceive their parenting experience, focusing on the positive aspects. Furthermore, since very little is known about how Italian parents perceive formal support, this study examined how they experience care and social services. Through a thematic analysis of 11 interviews, six key themes were identified: first-hand experience of disability, disability as a drive for change and personal growth, son-centered parenting challenges, social support to be improved, social support as strength. These themes confirmed both the presence of positive aspects associated with parenting a son with disabilities and the importance of social support for the parents and highlighted the necessity of improving formal support in the Italian context to provide an assistance perceived as efficient.

*Keywords:* children with disabilities, parental perceptions, social support, service experiences, thematic analysis

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## **Introduction**

There is general agreement that parents of children with disabilities face daily challenges, including managing their son's behaviors (Brown et al., 2011); accessing services (Ryan & Quinlan, 2018); and coping with a lack of social support (Tetreault et al., 2014). In many cases, parents are also required to not only manage their sons' disabilities throughout their lives (Beighton & Wills, 2017), but also set up a support network to care for their sons when they are no longer able to parent. These challenges and concerns can be sources of stress that, in the long run, negatively affect the psychophysiological functioning of these parents (Slattery et al., 2017).

For many years, research within this field focused on the negative outcomes associated with raising a child with disabilities. Fortunately, however, with the advent of the new millennium, there was a paradigm shift that led to an increase in research and perspectives emphasizing the possible advantages of parenting a son with disabilities (Blacher et al., 2013). These benefits are defined as "any indication that the family or any of its individual members have benefited as a result of the child with disabilities" (Helff & Glidden, 1998, p. 459). According to Blacher et al.'s (2013) tripartite model, the positive effects of parenting a son with disabilities are accompanied by a low negative view. When these parents experience the absence of negative perceptions and have the same positive experiences as the parents of typically developing children, they can be characterized as having a common benefits view. Finally, when these parents perceive unique benefits that are not experienced by parents raising typically developing children, then they can be characterized as having a special benefits view. Already Hastings and Taunt (2002) stressed on the functional role of positive perceptions as strategies that supports families to cope with the challenges of raising a son with disabilities.

Despite the change in the direction of research, which we believe is fundamental to understanding the experiences of this group of people in a more in-depth and complete way, it is still difficult to clearly define the benefits perceived by parents of sons with disabilities. In the literature, there are a limited number of models that consider the "positive" perspective and explore the multitude of complex elements that contribute to delineating these benefits (Beighton & Wills, 2017). It is however clear the call to invest more to change the common narrative that a son with disabilities has a negative impact on family members especially on their psychological adjustment (Hastings, 2016). The study conducted by Beighton and Wills (2017) sought to fill these gaps through qualitative research that investigated the experience of 19 parents of children with disabilities and outlined their positive

perceptions of the experience. Through a thematic analysis of the interviews, the researchers identified seven main themes: an increased sense of personal strength and confidence; changed priorities (e.g., being less materialistic, less selfish, and more content); greater appreciation for life; pleasure in the child's accomplishments; increased faith or spirituality; more meaningful relationships; and the positive effect that the child has on the wider community. Similarly, Slattery et al. (2017) conducted an online survey of 146 parents caring for children with developmental disabilities to investigate the circumstances under which parents of children with disabilities tend to perceive the most benefit. The researchers focused on social support and on positive appraisal which refers to cognitive strategies that individuals use to cope with stressful situations and reframe them positively as beneficial and/or meaningful. More specifically, they investigated the mediating role of these two dimensions in the optimism-benefit finding relationship. The results indicate that more optimistic parents are more likely to surround themselves with a supportive social network, which helps them reframe their situation and personal sense of meaning.

The study by Slattery and colleagues falls within a research line that considers the protective role of social support in perceived quality of life (Halstead et al., 2018; Misura & Memisevic, 2017; Robert et al., 2015; Lu et al., 2018; Almasri et al., 2018). The literature shows, in fact, that when parents perceive support from family members, friends, and social networks, they are less depressed, stressed and more satisfied (Abbeduto et al., 2004; Halsted, Griffith & Hastings, 2018). Social support is broadly defined as “the provision of physical, emotional, informational, and instrumental assistance that an individual perceives from their social networks” (Lu et al., 2018, p. 1182) and it is often categorised as formal and informal. Informal support, both psychological and material, is generally provided by family, friends, and parents of other children with disabilities. Formal support, such as financial support and reserved quotas, is provided through organizations and agencies. Recently Lu et al. (2018), for example, found that social support functioned as a mediator and a moderator in the relationship between parenting stress (i.e., an adverse psychological reaction to the demands of being a parent) and quality of life in a group of 479 parents of children with autism spectrum disorder aged 3–18 years old. The findings indicate that enhancing social support plays a key role in reducing the negative effect of parenting stress on life satisfaction. Considering the perceptions that parents and caregivers have regarding formal support emerges as essential since these perceptions can present an index of the parents' well-being and their adaptation to their child's disability situation (Robert et al., 2015; Ryan & Quinlan, 2018).

In the Italian context, literature on how parents of children with disabilities perceive social support is scarce. Cuzzocrea et al. (2016), for example, conducted a study that investigated the relationships between parental stress, coping strategies, and social support as perceived by the families of children with low-functioning autism, high-functioning autism, Down syndrome, and typically developing children. The results illustrated that the level of stress was negatively correlated with perceived family support for the parents of children with Down syndrome, while for the parents of children with autism, especially with low-functioning autism, social support seemed to have a negative effect. Furthermore, the study found that all groups of parents perceived formal support as very low, whereas “familial support” as the most important type of support.

As concern formal social support, Molinaro et al. (2017) considered the perceptions of both parents of children with disabilities and professionals regarding the modality through which services offer their support to families. Although the overall perception was positive, both parents and professionals suggested that more effort is needed to increase information-sharing with families. Additionally, parents reported a lower perception of family-centred care provision when children were treated by services with limited financial resources.

Keeping in mind the emerging interest in the positive aspects of the parenting experience and the role played by support, this research has two main purposes. Firstly, it aims to investigate the perceptions that parents of sons with disabilities have about their experience, with special attention given to positive aspects. Secondly, with the intention to reduce the gap in the reference literature concerning the Italian context, we explore parents’ perceptions regarding the social support they receive, with a particular focus on formal support.

## **Participants**

In this study, 11 parents of sons with disabilities were interviewed. Among the interviewees, there were four couples, including a couple with two children with disabilities. Their ages ranged from 35 to 60 ( $M = 50.55$ ;  $SD = 7.97$ ), and six interviewees were women (54.55%). As for their educational qualifications, seven (63.64%) ended the compulsory school level, and four had a university degree (36.36%).

The study included sons with disabilities aged 5 through 31 ( $M = 17.09$ ;  $SD = 9.13$ ); of them, four sons (50%) had intellectual disability, and four ones

had a psychomotor disability. Of these ones, only one was an only child, while another was adopted.

Table 1. *Summary of the characteristics of the participants and their child(ren)*

Parent				Sons			
No	Age	Gender	Occupation	Age	Gender	Diagnosis	Position in Family
1	60	F	Retired	27	F	Down syndrome	Youngest of two
2 3	54 54	F M	Tradeswoman Blue collar worker	31	M	Spastic tetraparesis	Middle child of three
4 5	53 53	F M	Office worker Educator	17	F	High-functioning pervasive developmental disorder	Youngest of two
6	52	F	Food and wine operator	14	F	Angelman syndrome	Only child
7	53	M	Blue collar worker	11	M	Psychic disability	Adopted. Youngest of two
8 9	35 35	F M	Housewife Office worker	5 5	M M	ASD ASD with hemiplegia and intellectual disability	Two siblings
10 11	53 54	F M	Housewife Craftsman	15	F	West syndrome and psychomotor retardation	Youngest of three

## Measurement

To measure participants' perceptions both about their role as a parent of a son with disabilities and about formal social support (e.g., social service, day care centres, school service), semi-structured interviews were conducted. Most of the

interviews were carried out in the homes of the participants, so that they felt comfortable expressing their perceptions and emotions. A few of the interviews were conducted by telephone. After reading the informed consent statement and collecting personal data, we asked the following open-ended questions: What is a disability to you? What difficulties do you face as a parent? What strategies do you use to cope with difficulties? What positive aspects have you found in being a parent of a son with disabilities? How do you consider the relationship you have with the public services to which you turn most frequently?

### **Data Coding and Analysis**

The interviews were recorded and then transcribed verbatim. All identifying information was removed during the transcription process. The data analysis was performed following the principles of thematic analysis and the inductive method (Braun & Clarke, 2006). Next, we generated the initial codes, which involved repeatedly and carefully reading the data from each interview. Finally, we grouped and reorganized the initial codes according to common themes.

### **Results**

Two macro themes emerged from the thematic analysis: being a parent of a son with disabilities and perceived social support. The themes and the codes underlying each theme are presented next.

#### **Macro Theme 1: Being a Parent of a Son with Disabilities**

##### **Theme 1: Experience Disability First-Hand**

The reflections shared by parents testified the difficulties they experienced during the initial stages (e.g., communicating the diagnosis). Over time, they were able to positively overcome these difficulties and make space for other operational difficulties, such as securing access to services, finding information, and obtaining aid. Several parents shared that they gained greater knowledge and developed a deeper understanding of the practical meaning of disability. In several interviews, it emerged that how a person with disabilities perceives their environment affects their ability to achieve their development goals. Finally, some parents recognized the uniqueness of their son's development compared to children with typical development, and in some cases, they also confirmed that the lack of sons' autonomy can lead to limitations on their lives as partners and adults.

Table 2. *Sub-themes for the key theme “experiencing disability first-hand” with illustrative quotes*

Sub-themes and Illustrative Quotes	Frequency
<p><i>Insight on disability</i></p> <ul style="list-style-type: none"> <li>- I had already known about disability through the civil service, which I carried out in a service for the mentally disabled, but it is one thing is to relate to external people, and it is another thing to have someone who is a bit “weird” at home (#5).</li> <li>- With M. and L., my knowledge about disability has changed; before, I knew very little about disability from my personal experience, of course (#9).</li> </ul>	7 (64%)
<p><i>My son and typicality</i></p> <ul style="list-style-type: none"> <li>- The perceptions we self-impose can be a difficulty. If I compare my son to a five-year-old neurotypical, then we obviously find differences in social relationships. [...] If I compare L. and M. to other neurotypical children, then yes, [I would perceive] difficulties. On the other hand, if I follow their path, then I see no difficulty (#9).</li> <li>- We can’t do the things other married couples do, even go for a pizza (#2).</li> </ul>	7 (64%)
<p><i>Accept disability</i></p> <ul style="list-style-type: none"> <li>- The first difficulty, in my opinion, is in understanding and accepting. When they gave us the diagnosis, the most difficult part for me was understanding what it meant, internalizing it, and reacting (#9).</li> <li>- For my in-laws, initially, it was more difficult to accept M., both because they come from another era and because my husband was an only child, and they imagined everything was perfect (#1).</li> </ul>	5 (45%)
<p><i>The social context influences the disability</i></p> <ul style="list-style-type: none"> <li>- I see disability as something that slows you down, more than anything else, because the society we live in is organized according to certain rhythms, and obviously this makes this diversity of abilities clearer (#8).</li> <li>- It is society that makes them feel disabled (#1).</li> </ul>	5 (45%)

## Theme 2: Disability as a Push for Change and Personal Growth

The parents we interviewed perceived the experience of raising a son with disabilities as a strong driver for personal growth and one that changed their perspective on life. In general, the parents said that they matured and became stronger temperamentally. In some cases, the parents developed a resilience which allows them to face the many difficulties they encounter. Being parents of sons with disabilities led many interviewees to change their priorities in life: they take

nothing for granted, they consider themselves less materialistic, and they are more capable of identifying the values upon which to base their lives. Other positive aspects that emerged involve developing significant interpersonal relationships and a lifestyle focused on a continuous search for solutions. In fact, several parents said that to manage their son’s disability, it is necessary for them to shift strategies and adapt to the changes and needs of their son.

Table 3. Sub-themes for the key theme “disability as a drive for change and personal growth” and illustrative quotes

Sub-Themes and Illustrative Quotes	Frequency
<p><i>Changed priorities</i>            - Another aspect that I was able to make positive was knowing how to give a different weight to things than before – people and situations – which allows me to face everything that happens to me during my day from a different point of view, give a magnitude to the facts in a different way. Before, a problem even at work might have seemed insurmountable. Now, this considered problem, compared to the other, has become much less insuperable (#9).            - For me, it is an opportunity to learn and understand the values of life. A child like this makes you think about the value of certain things: you give less importance to material things, or rather, you see them differently (#11).</p>	8 (73%)
<p><i>Lifestyle aimed at the continuous search for new solutions</i>            - You must always think about what would be better. You must be able to find the right thought among the thousand thoughts (#4).            - The strategies in disability must be studied day by day; it is a discovery (#6).</p>	8 (73%)
<p><i>Personal growth</i>            - L. forced us to grow and change, even when we never thought we would (#5).            - [Our daughter] strengthened her character; she made me combative (#6).</p>	6 (55%)
<p><i>Meaningful relationships</i>            - The people who are close to me are sincere people who love us. Since M. has been around, we learn to know people, – the hypocrisy is great, and you recognize it immediately. M. has an edge. It makes me understand all those who are fake. I have done so much cleaning in my life. She has a sensitivity: she makes me understand who beautiful inside is, and so I surrounded myself with real and authentic people, thanks to M., who treat us well and above all do not pity us (#1).</p>	3 (27%)

### Theme 3: Son-Centred Parenting Challenges

Some parents stated that they are satisfied and happy as parents when their son with disabilities is calm and achieves important and sometimes unexpected

goals about their autonomy and well-being. However, alongside these positive aspects that highlight the joy of being a parent, there are at least two major concerns: concerns about their son's future and concerns about their other children. In the first case, parents question what their son's quality of life could be like in terms of accommodation, employment, relationships, care and affection in what is known as the "after us" phase. In the second case, parents are concerned that the brothers or sisters of the son with disabilities may in some way be affected by the disability and are eager not to place a burden on them.

Table 4. *Sub-themes for the key theme "child-centred parenting challenges" and illustrative quotes*

Sub-Themes and Illustrative Quotes	Frequency
<p><i>Son's wellbeing and accomplishments</i></p> <ul style="list-style-type: none"> <li>- Since arriving in Italy, I have seen a lot of progress, and for me it was a great satisfaction. I don't care whether he is a phenomenon or that he brings home a 10 but that he is calm and manages to reach his small conquests, which are much more important to us (#7).</li> <li>- We have been given the opportunity to take R. to the pool. I cannot enter, and there are specialized staff who follow her. When I went to get her, and I pulled her out of the water, she smiled at me blissfully. She was happy and calm. Her serenity was a big goal for me – a real joy and something that satisfies (#10).</li> </ul>	7 (64%)
<p><i>The future as a source of stress</i></p> <ul style="list-style-type: none"> <li>- The classic mechanism of thinking about the future has been triggered. After us, what are the current support structures, family homes, etc? I was thinking about the quality of life for L. I was thinking about what she could have done, the objectives that she will be able to achieve (#5).</li> <li>- When we are no longer there, who will take care of them? This society will be ready to welcome them, so the difficulty will be the wild race to somehow try to build their future already, now, while they are children, and hope to be there in their future in some way, but also considering our absence. Will I be able to be physically there when they grow up, to gently prepare them for my detachment? (#8).</li> </ul>	4 (36%)
<p><i>Brothers and sisters</i></p> <ul style="list-style-type: none"> <li>- [If we wanted] to go and eat a pizza, or if the other brothers are at home and then M. stays with them, [or we stay at home]. I honestly don't find it right to burden my other children, so many times we stay at home (#2).</li> </ul>	3 (27%)

## Macro Theme 2: Perceived Social Support

### Theme 1: Social Support to Be Improved

Several parents shared concerns they have in relation to formal social support, which have resulted in negative perceptions. They suggested possible avenues for intervention to make the available support more efficient and perceived as valid. According to some parents, there is a need to increase the number of professionals with skills in managing a disability and who are more willing to meet and understand the needs of the person with disabilities and their families. This need is closely linked to the development of a network of services where professionals are willing to interact with each other to provide the individual and families with support characterized by common and shared objectives. For this to be possible, more economic investment is needed in services that support families and their sons with disabilities. This could guarantee more widespread and preventative help and would remove the burden on parents to fight for their sons to ensure that their rights are recognized. Some parents also highlighted how often they receive inaccurate or missing information from professionals, which leads their families to have to seek information independently and therefore deprive their sons of the attention they need. In general, the data shows that parents harbor feelings of mistrust, frustration, disillusionment, and anger towards formal social support.

Table 5. *Sub-themes for the key theme “formal social support to be improved” and illustrative quotes*

Sub-Themes and Illustrative Quotes	Frequency
<p><i>Need for competent professionals</i></p> <p>- A month ago, the centre sent a new transport operator of a certain age who was not yet able to “manage” a person with disabilities. I saw how he maneuverer the wheelchair and how he took my son to get him in the middle. I felt insecure leaving him to the operator, not because he was a bad person, but because I was thinking about my son (#2).</p> <p>- For us to follow the American model – that is, therapy at school – it is expensive economically. Last year, we tried. Their therapists did an hour in school, but the teachers were not interested in learning the method. They didn’t ask the therapists any questions. They followed the therapists’ directions correctly when they were there, and that’s it (#9).</p>	6 (64%)
<p><i>Need for integrated services</i></p> <p>- It is as if all the services were dots on their own, and the line that connects the dots must be created by the family, while in my opinion this line should be created by those who follow them. It shouldn’t be the task of us parents to convince everyone that once you have chosen a path, you must all follow it.</p>	4 (36%)

<p>This union should become automatic; the services should talk to each other. The services may also be excellent, but until they are combined, there will be a waste of resources. Now all our judgments are given to the dots (#8 and #9).</p>	
<p><i>Need for more economic investment</i>  - M. does many activities (swimming and cooking), and sometimes the services do not help you. I asked for help for transport to the social services of the municipality, and it was not granted to me, because I was retired, until my husband got very aggravated, and my father-in-law was sick. Only when I couldn't take it anymore did they activate the service (#1).  - To have the aids – wheelchair, stairlift, etc. – because you can only have one aid. Otherwise, you must buy them. If a person is disabled, then he is disabled. You cannot give him one thing and not the other (#2).</p>	4 (36%)
<p><i>Fighting for the sons</i>  - Throughout the school period, there were constant fights, even during school hours. I threatened the principal to leave my son in the office. Another fight was for the benefits: the support teacher and the operator (#2).  - The fight for rights is hard. You find closed doors. Already as a parent, it's a difficult life. You don't have an extra life, they don't give you a hand, and then you must behave as "bad" (#6).</p>	4 (36%)
<p><i>Inaccurate or missing information</i>  - After the diagnosis, no one gives you information. They do not tell you what benefits you can access, what to do, or the places where you can find out. I have consulted other families who have had the same problems as ours, because the services provide you with little information. They stop at the diagnosis without showing you the general range or if you can access other services (#4).</p>	2 (18%)

## Theme 2: Social Support as a Strength

Despite highlighting critical issues, the parents interviewed also highlighted some strengths. Some of them stated that they perceive service professionals who support their sons as resources, and this allows them to experience positive feelings of relief. In addition, some parents claim that they feel support from friends, family, and associations, and this is an additional source of relief. More specifically, some have highlighted how sharing strategies with their partner and having mutual help constitute significant resources in tackling difficulties together and developing strength.

Table 6. *Sub-themes for the key theme “social support as a strength” and illustrative quotes*

Sub-Themes and Illustrative Quotes	Frequency
<p><i>Professionals perceived as resources</i></p> <ul style="list-style-type: none"> <li>- The operator who has followed M. since she was in elementary school has, for M. and for us, become a point of reference (#2).</li> <li>- The people we have relied on, between public and private personnel, have become resources (#9).</li> </ul>	5 (45%)
<p><i>Positive formal support</i></p> <ul style="list-style-type: none"> <li>- The [day] centre is a positive element; it makes me calm (#2).</li> <li>- One year, when D. was in fourth grade, I asked a psychologist to set up a meeting with D.'s classmates because the children did not know how to relate to him. They told me that the children listened to the doctor, and then they asked him a lot of questions. [...] After two or three days, the relationship changed because they understood what D. had, and the mothers of the children called me to thank me.</li> </ul>	5 (45%)
<p><i>Support from friends and family</i></p> <ul style="list-style-type: none"> <li>- We also asked for help from the families of our friends, who helped us a lot, gave us many info, and many times involved us in messages or trips (#5).</li> <li>- Fortunately, we have found this association that helps and gives us relief (#6).</li> </ul>	(45%)
<p><i>Mutual support to overcome difficulties and become stronger</i></p> <ul style="list-style-type: none"> <li>- My husband and I have always shared strategies, or otherwise we did not go forward. It was not easy. I sometimes had less patience, and instead my husband had more. With M., you must control the obstacle: when one thing didn't succeed, my husband and I would get in two and one at a time we tried to solve. [...] If with one approach he didn't succeed, then I tried another one. Having shared ideas was important.</li> </ul>	3 (27%)

## Discussion

There is no doubt that for some parents, having a son with disabilities can lead to high levels of stress and a lower quality of personal and family life due to the constant daily challenges. However, this study confirms that the parents themselves perceive some positive aspects deriving from the situation of their son's disability (Blacher et al., 2013).

One aspect highlighted by parents' concerns a motivational boost to personal growth and a change in their perspective on the world and on life in general. This can mean becoming less materialistic, giving a different weight to things, and identifying the values considered to be of greater importance in life. Another aspect concerns the possibility that the lived situation offers a chance to develop meaningful and authentic interpersonal relationships, which constitute an important social support. The situation of disability leads some parents to adopt a lifestyle aimed at seeking strategies that allow them to optimally face daily

challenges. These strategies also allow parents to develop a sense of self-efficacy in identifying the most suitable solutions for their son's needs. These results show many similarities with Hastings and Taunt's proposal (2002). Among the positive aspects of raising a son with disabilities they, in fact, report the presence of opportunities to learn and develop as parents and human beings, to increase personal strength and confidence, to develop a new life perspective, to acquire new skills, abilities, and new career opportunities. These perceived positive aspects can be construed as the outcomes of a process that parents implement to reframe their situation with adaptive coping strategies and testify the value of assuming a positive perspective (Beighton & Wills, 2016; Slattery et al., 2018).

In general, parents involved in the study developed a greater awareness of the meaning of disability. This insight is the result of a daily knowledge process that led them to accept the situation of disability, albeit not without initial difficulties. In defining disability, there is a tendency on the part of the parents to attribute some weight to the role of the social context in which a person lives. These reflections are in tune with the conceptualization of disability promoted by the International Classification of Functioning, Disability and Health (2001), according to which the situation of disability represents the consequence or the result of a complex relationship between the health condition of an individual, personal factors, and environmental factors. Furthermore, especially parents of children and adolescents who took part in the study showed that they can value the goals achieved by their sons, considering their uniqueness in cognitive, behavioural, and physical development compared to a son with typical development. This, however, does not mean that they do not perceive limitations to their own desires and autonomy. A similar result also emerged in the study conducted by Rapanaro et al. (2008), who investigated the possible positive aspects and negative impacts of challenges experienced by a sample of 119 parents of young adults with disabilities in their transition to adulthood. In a qualitative analysis of the questionnaires administered, the parents named "a lack of freedom and independence at a time when a parent would normally be gaining some independence from care of their children" as a stressful outcome (Rapanaro et al., 2008, p. 42). Additionally, due in part to the lack of autonomy of their child, parents perceived the future as a source of stress. Their main concerns are to create a network to support their son when they are no longer able to do so, and to do it in a way that burdens their other children. Finally, in line with the results obtained by Hastings and Taunt (2002), the parents in our study confirmed the presence of positive feelings generated by perceiving and seeking the well-being of a son with disabilities. Surprisingly, no worry about the future was mentioned by the older parents with adult sons. We can speculate that for these parents this is not an issue because they have already arranged some planning for the future or, on the contrary, that this is so painful for them that they refuse to share their thoughts about this hot topic given their age. Further investigation should be conducted to give them more opportunities to discuss and provide them support if needed.

As for social support, when it is present, it is perceived by parents as an important positive aspect that favors their well-being and that of their son with disabilities. Sources of support that emerged in the data included friends, family, and associative networks. The parents tended to value mutual support with their spouse or partner in overcoming difficulties and becoming stronger. This finding echoes the study conducted by McIntyre and Brown (2018) who investigated the perceptions of 78 mothers with young children on the autism spectrum on the use and usefulness of their social support. The data showed that approximately 90% of the sample relied on their spouse or partner as a resource for support and help.

Regarding formal social support, some parents perceived services and professionals (e.g., teachers, doctors, and social health workers) as valid resources who help their sons with disabilities achieve their personal growth objectives. The positive feelings reported by parents (e.g., relief, peace of mind and happiness) and associated with this experience could positively affect the quality of family life. For this reason, it is hoped that increasingly more families will be able to take advantage of formal social support services. This, however, will also require improving those aspects that parents have highlighted as problematic and a source of stress, including developing an integrated network of services; providing information that is accurate and consistent across services; investing in the training of professionals; and investing more economically in the field of disability to provide support that covers the needs of the family, and not only in cases of extreme need. The call for a greater and equal financial investment then emerged as salient for older parents that reveal moments of difficulties to receive concrete supports for basic aids such as a wheelchair. Finally, developing and improving formal social support would bring an additional advantage: Parents would no longer be forced to fight for the rights of their sons with disabilities. This finding, which emerged from the data, could reduce their energy, time, and financial expenditure, which could then be redirected to meet the needs of the son and the family.

To conclude, despite the limited number of parents involved and their heterogeneity, this research confirms existing findings in the literature which highlight the presence of both negative and positive aspects related to the experience of parenting a son with disabilities. Additionally, positive aspects are perceived in relation to the parent's relationship with their son, the benefit of social support when it is present, and the change in perspective that the disability has brought about for the parents themselves. The downsides are focused on what does not work or does not exist within the current framework for formal social support services. These shortcomings compound the difficulty of raising a child with disabilities, difficulties which parents must solve daily. It is evident that it is necessary to invest more in services that support people with disabilities and their families. Providing high-quality social support that is positively perceived by families could increase the families' well-being and the quality of family life and

personal life for those people living in a situation of disability, thereby further promoting social inclusion for the benefit of the entire community.

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