

Being a parent of a child with a disability in Italy: from diagnosis to starting school

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ABSTRACT

The birth of a child with a disability is a critical event for the whole family. Through in-depth interviews and two focus groups, I collected the testimonies of a group of parents who talked about their experience from being given the diagnosis to their children starting school. The data were analysed using a phenomenological approach in order to report the participants' points of view. The results show the importance of three key elements that can affect the experience: how the diagnosis is communicated; a comparison with what society defines as normal; family involvement in the creation of a program that helps the child with a disability to start school. Collaboration between teachers and families can help families to take an active role and to design interventions that will enable both the child and the parents to have positive experiences regarding school.

ARTICLE HISTORY

Received 4 September 2014
Accepted 19 March 2015

KEYWORDS

Disabled children; family; diagnosis; school

Introduction

'What will life be like for my son/daughter?' This is one of the crucial questions that unite parents when their child is born with a disability. It is characterized by different experiences that are a potential source of difficulty and destabilization for the family (Ackley and Ladwig 2013; Kisler 2014; Zano-bini, Manetti and Usai 2002). When a child comes into the world, there is a sort of magical encounter between what is desired and what actually happens, between parentals' expectations and what in reality is (Ergün and Ertem 2012; Montobbio and Grondona 1994).

Pontiggia (2000) notes that this experience can be seen through two lenses: (i) the grieving process or (ii) a new birth. These two concepts represent very diverse experiences, but they also highlight two different conceptions of disability and the commitment that society must make to these families. With regard to the grieving process, the birth of a child with a disability is associated with a negative experience. The literature emphasizes the narcissistic wound that can be created at the birth of a child with a disability (Chianura and Dellarosa 1996; Huang, Kellett and St. John 2010) and the discrepancy between the expectations and the image of the child who for nine months was the fantasy but who in reality appears to parents as an 'imperfect' child. In addition, the literature stresses concerns regarding the future of this child but also of the family, and the crisis that parents may go through as a couple (Boer, Dunn, and Dunn 2013; Hellinger 2004; Sloper 1999; Stern 1999).

Concerning the diagnosis, parents often report never forgetting the exact words spoken by the doctors: they remember with gratitude those who gave them their time, provided explanations, and painted an acceptable image of the child and their future. Many times, however, this experience is characterized by misunderstandings, communication that is superficial, hasty, and sometimes reserved for just one parent (Ferri 1996; Grispino 2007; Hasnat and Graves 2000). After receiving

the news, parents often manifest feelings of confusion and bewilderment or denial accompanied by the invention of a non-existent capacity (Grispino 2007; Sorrentino 2006). This moment is defined by Pontiggia (2000) as medical shopping, and it is characterized by exaggerated medical assessments and forecasts in an attempt to try to understand more thoroughly what has happened. Thus, parents keep the hope alive that they will receive better information than they already have and thus in some way be able to escape from the disability (Perez-Pereira and Conti-Ramsden 2002). It is also an attempt to satisfy the need for reparation for the damage for which, whether consciously or not, parents feel responsibility and guilt (Coppa 1997). A kind of medicalization of time and expectations is created in which parents are lost between pilgrimages to specialist centres (Caldin 2004; Trute, Benzies, and Worthington 2012). There are many authors who, like Pontiggia (2000) and others after him, identify this period with the concept of the new birth, understood as a new opportunity that leads to a focus that is no longer on the already given, which limits (which must be known), but rather on the new possibilities of what can be built together (Heron 2002). The ability to maintain the hope of doing good is a therapeutic and educational factor; it is also contagious and enables continual growth (Caldin 2012). Parents need to be supported and to find adaptation strategies and be calm, so that the child can grow with them in a more balanced way. This in turn leads to the possibility of overcoming the wound, and also of recognizing skills and learning to accept their feelings (Battaglia 2000). Rather than focusing on the disability itself, the family is then considered to be involved in a process of adaptation which is vital to ensuring that this adaptation is based on resources that can enable (Favia 2003; Zanobini and Usai 1998). This change in perspective is the result of a number of important studies that have placed the family right in the centre. Some surveys (Canevaro 2007; Treille Associazione 2011) have focused on the experiences of various individual cities, while others on the needs expressed by families. The analysis conducted by D'Alonzo (2002) showed that the perception of assistance was rated lowest during the preschool years and when the diagnosis was communicated. Usai, on the other hand, involved 91 families in order to identify proposals for action, guided by a non-pathologizing approach that manages to combine the need for integration and to focus on the developmental processes of households (Zanobini, Manetti and Usai 2002).

The grieving process, and the new birth, refer to two different conceptions (or models) of disability. The first one is a medical model which sees the disability as a personal tragedy that affects a few unfortunate people. If the disability is a tragic wound, society's task/job, therefore, is to help parents through the mourning process. This is a medical problem and the 'solutions' for this problem are also assigned to doctors. The second one, instead, is a different model, called the social model of disability, which sees disability as the interaction between the characteristics of an individual and his environment (Barnes 2000; Valtellina, 2006). According to this model, disability is a social issue and has to do with the environmental barriers that prevent individuals from enjoying their rights. Precisely because of this social connotation, it is society's duty to remove all of these barriers and encourage the participation of all individuals in the life of society (Shakespeare and Watson 2001).

The difference between the two models becomes apparent when children enter the world of school and they begin to use the services that are offered to them. It is a critical moment for several reasons. Firstly, parents often experience social exclusion and loneliness accompanied by pessimism, for which there seems no solution. When they do not feel understood, they tend to isolate themselves in pain, and even the simplest tasks, such as playing with their child or searching for a restaurant, are considered embarrassing (Grispino 2007). Secondly, when starting nursery school the children are invested with their first 'social role'. Somehow this step corresponds to a 'debut in society', which is where they are recognized as a young member. Thirdly, this also involves beginning a new experience for the children and parents: being compared with other children (Welch et al. 2013). Goffman previously (1983) wrote that parents, accustomed to their children's difference, interact with them naturally but may be afraid that disability could be a burden on other children (Hellinger 2004). It becomes almost inevitable then that there will be a comparison between the activities done by classmates and the child with a disability.

In 1977 in Italy, special schools for children with disabilities were abolished and the long tradition of integrating children with disabilities into mainstream schools began. The school takes on the needs of these children through the introduction of styles and patterns of work that are supposed to help improve the conditions of all the pupils. The evolutionary journey of children is supposed to be built in a climate of everyday hospitality, warmth, and emotional skills (Rondanini 2011).

The physician's written diagnosis accompanies the child in school. In addition to highlighting his disability, this document contains the request to have a special teacher and indications of the cognitive abilities of the child. Special support teachers are provided to help these children. They prepare a personalized plan for the child, which can be accomplished within the class or through individualized actions that require the child to work alone, away from his/her classmates. This project cannot be planned only by teachers but requires the active involvement of the family and of the specialists who take care of the family (Causin and De Pieri 2006). This involvement represents a big change for a family, who are already involved in a network of services, and a role they are not always keen to accept. Starting school is a time when the whole family can create a hermeneutic circularity that makes them question themselves and situations (Cairo and Martinazzoli 2013; Whiting 2013).

Where does this begin? Within the school, children need to find skilled personnel, but they particularly need the relational qualities of all those involved, who need to listen actively and provide clear information (Bichi 2011; lanes and Cramerotti 2007; Perrotta 2009; Sorrentino 2006). It also marks the point where families may stop researching the pathology and instead start focusing on coping strategies, as well as beginning an adjustment process, and examining the quantity and quality of social support. The first steps involve the crucial contact between families, schools, and other educational institutions (Causin and De Pieri 2006).

The aim of this research is to identify the 'key moments' and emerging issues that affect parents who have a disabled child during the first years of life. This work aims to provide a snapshot of the experiences of parents of school-age children with a disability in order to highlight the resources and daily difficulties together with their relationships with the school and, more generally, with the community. Through these experiences, it will therefore be possible to envisage support for the family and the lives of children with disabilities.

This article presents some of the most significant results of the research related to family communication of the diagnosis and the child starting school.

Methods

Participants

I listened to the accounts of mothers and fathers of: three boys with Down's syndrome; one girl with nanosomia; two girls with autism; two boys with a sensory impairment; one boy with Dravet syndrome, and one boy with Dystrophy syndrome; two children with a visual impairment; three girls with a developmental disability, and four boys with a mild cognitive delay.

Each pair of parents was interviewed together during their children's first year in Milan, the largest city in northern Italy, when the children were three years old. The reason for this was the desire to examine the impact on the children of starting school for the first time. Many researchers recognize that a detailed interpretative account of cases is realistically possible with a small sample, thus in simple terms this is sacrificing breadth for depth (Smith 2007). The contact with the families took place through teachers who acted as mediators. This ensured a more familiar context and, on the other hand, encouraged respect for privacy, especially for those families who preferred not to be involved in the study.

The research was carried out with the permission of all people attending the services involved: parents and teachers. The data collected during the research were treated on a confidential basis. The anonymity of participants has been protected throughout the research process and will be in any future published work. The results come from a precise and detailed analysis of the collected

materials. The answers from the interviews were not taken out of context and small observations were not discussed without putting them in the appropriate context.

Data analysis

Consenting parents were interviewed and their experiences were collected from the time of being given the diagnosis to starting school (usually nursery school). Interviewing seemed the most useful tool for eliciting the subjects' perspectives, their experiences, and feelings (Corbetta 2007; Weiss 1995). A qualitative interview is a fundamental method for learning about the experiences of other people. It is generally organized around a set of predetermined open-ended questions, with other questions emerging from the dialogue between the interviewer and interviewee/s. The most important questions in this study were the time and manner in which they received the diagnosis, the experiences that characterized this communication, their relationship with the specialists, the choice of nursery school in which to enrol the child, the concerns and hopes that preceded the experience; the potential and limitations that emerged while attending nursery school.

The conversations were recorded and transcribed (with the consent of the participants) and analysed using a phenomenological approach (IPA), aimed at highlighting, as much as possible, the points of view of the people surveyed. IPA aims to understand the experience itself and how participants make sense of it. It is therefore concerned with the meanings which those experiences hold for the participants. Through purposive sampling, IPA finds the most closely defined group for whom the research question will be significant. How the specificity of a sample is defined depends on the study; in some cases, the topic under investigation may itself be rare and may define the boundaries of the relevant sample.

The researcher therefore tries to leave aside his/her own preconceptions, beliefs, and judgments in order to get to the essence of the phenomenon (Trinchero 2004). A two-stage interpretation, or a double hermeneutic, is involved. The participants try to make sense of their world; the researcher tries to make sense of the participants trying to make sense of their world. IPA is therefore intellectually connected to hermeneutics and theories of interpretation (Smith 2007).

In collecting and analysing the data, I followed a Grounded Theory Approach with initial and focused coding, writing memos, and developing blocks for the theory development through continuous comparisons (Charmaz 2014) using the software Atal.ti. The data that emerged from the analysis were discussed with the participants in two focus groups, which enabled families to better understand and share their experiences. Focus groups are a form of group interview that capitalizes on communication between research participants in order to generate data. Although group interviews are often used simply as a quick and convenient way to collect data from several people simultaneously, focus groups explicitly use group interaction as part of the method. This means that instead of the researcher asking each person to respond to a question in turn, people are encouraged to talk to one another: asking questions, exchanging anecdotes, and commenting on each other's experiences and points of view. This method is particularly useful for exploring people's knowledge and experiences and can be used to examine not only what people think but how they think and why they think in that particular way (Kitzinger 1995).

Results

Theme 1: diagnosis as the Stations of the Cross

The experience of being given the diagnosis differed mainly in terms of the disability but was always a significant moment. Some parents said that they had already been informed during the prenatal examinations (as in the case of Down's syndrome). In those cases, the period before birth was a preparatory phase, but also a time when parents tried to refrain as much as possible from making comparisons with reality:

From when we learned that our son would have Down's, we had a few months to try to prepare ourselves; when he was born we realized that it really was true, that things were not going to change. Our son was here, you've got him in front of you.

Others, however, said that the discovery came at the end of a painful and sometimes long ordeal. It was like making the 'Stations of the Cross', remembered one of the couples interviewed:

Our son was born apparently healthy, only after eight months we realized that something was wrong, and our ordeal started. They asked us if our son was interested in the games that we proposed, if he grasped objects with both hands, and then followed us with his eyes, but we could not understand why these questions were being asked. Nobody said anything, even though we had the feeling that something was not right, but we did not know what. They only asked us questions, but gave no answers to our questions. After more months of suffering came the diagnosis: autism, but no one told us what it all meant.

The experiences of the other respondents were similar: 'It was the day of his first birthday, I still remember, we were in the hospital, and it was the third hospital that we had tried, so we celebrated his birthday there.' In other cases, the diagnosis happened as a result of the determination of the parents:

It was especially my wife who insisted ... there was a period when she persisted in saying that there was something wrong with our son and the doctors responded that there was no need to worry, that she [the wife] was suffering from anxiety, and there was nothing out of the ordinary. She did not believe this though, and so she insisted on investigating, and in addition to her fears, she also had to endure being labeled an apprehensive mother, but she was right.

When parents reach a diagnosis, they may simply be resigned or they may try to get a second or third opinion:

We could not believe it, and so we started to get other opinions, but they all said the same thing, every time we left with hope, and every time we came back, stronger than before, but it was like banging our heads against a wall, and it became more and more difficult to get up, and so we stopped trying.

Theme 2: diagnosis as a starting point

Then there are experiences in which the communication of the diagnosis, rather than being a point of arrival, becomes an endless starting point:

When we were informed that our son had Dravet syndrome, the doctors did an endless series of tests, and we thought it was over, but no, we were told it was a rare disability, one of those disability that are studied together with the children who are affected. We discovered shortly afterwards that there is no cure and with every step he took, a life-saving drug had to be available and administered promptly in case of a crisis (and for a period these crises were every week) and each year he spent three weeks in hospital, without sleeping at night, with wires attached to him everywhere, which was painful for him, but also for us.

The communication of the diagnosis is a starting point for several reasons. Often information relating to the disability is scarce and parents embark on a new adventure for new information. It is a starting point because every day they discover what new implications the disability has for their child's daily life. Parents need to understand how to help their child and how they can encourage his/her growth. Every day parents then learn behaviours/strategies/tactics that other people adopt to view and interact with them and their child.

For all these reasons, starting school becomes a particularly critical time which the parents, as well as the children, need to prepare for.

Theme 3: diagnosis as a wall or a label

When a child with a disability starts school, they are supported by a special teacher who provides an individualized program with objectives that may be similar to those of other students, or specifically

based on the child's ability. This possibility of constructing a special program, different from other children's, represents a major stumbling block for parents:

The diagnosis can have two functions. It may be helpful if you can understand what the child's difficulties and the ways to help him are. The diagnosis is also helpful because it guarantees/ensures the assistance of a support teacher. The diagnosis, however, can also be a stigma, an obstacle for the child. It is a label, it says that the child cannot be like the others. The diagnosis can also be a wall, a mountain to climb.

Thoughts immediately turn to the communication of the diagnosis: 'Thinking back to the diagnosis, and as long as the doctors were communicating the diagnosis, the possibility of a positive future for our children, the possibility of being able to help to our children.'

In addition to this difficulty, parents also have to relate to other parents and children:

I understood a little more about my daughter when I started to see her in the nursery playground, she was with other kids, but she was alone. She does not interact, she was in her own world, gradually I understood the meaning of the diagnosis they had given me better, but I have also witnessed children's ability to approach her, to try to involve her in their games with a simplicity that is almost unsettling.

This experience of confrontation is sometimes seen as positive, but it certainly carries a strong emotional charge:

I remember the effort required in the early days at the gate, the parents were competing to recount the exploits of their children. I listened to them, but I did not know what to say. My heart sank while I thought about how hard it is for my child to make a minimal gesture. I thought that I understood, but maybe the others didn't.

The difficulty is related to the fact that the parents of children without disabilities often exaggerate their children's skills, whereas the progress of children with disabilities may be barely noticed and not valued by other people. The fear that their child may not be accepted by his/her peers or may be labeled as 'different' leads some parents to refuse special projects and request their children be given the same treatment as other students:

We have rejected the construction of a customized path, as well as the presence of specific educational figures. We wanted to see what he could do on his own, in a context similar to that of the others. The choice of the structure has depended on this: we discarded all those schools where they asked us to accept a figure to take care of our daughter.

The right guaranteed to children with disabilities, which should help them, became an obstacle for parents, and they would refuse it. These parents see the presence of a support figure as stigmatizing for their children and that emerges consistently when parents compare children:

In other cases, however, a personalized program, along with a support teacher, are seen as a resource. Sometimes parents can feel reassured by the presence of an adult who gives special attention to their child: We were terrified that something might happen to him, that he might be alone if something happened, and it was better to have someone who could be a point of reference for him, which reassured us.

Theme 4: diagnosis as a protection or an opportunity

In other circumstances, however, the parents ask teachers to create an environment that suits their child and their needs:

When we had to enroll our daughter at the nursery school we made preparations a year in advance. We contacted the school head and explained the situation, as we wanted to prepare, and we asked for help. We had several meetings and, a few months before the start of lessons, we had a meeting with other parents to explain who she was and what her difficulties were.

The presence of a support teacher working on an individualized project prepared with the family is more than just a response to the need for reassurance. It provides the opportunity to help children with disabilities to develop their skills in order to ensure a positive experience in school.

To describe this, one set of parents used the image of a golf course:

Our daughter is the golf ball, the club, and we, along with the services, swing with the right amount of strength to make sure that the ball not only goes in the hole, but with as few strokes as possible. The metaphor of the course is particularly suitable because in this sport, to allow less experienced players to be able to compete 'on equal terms' with the best, a handicap system is used. This means that those who are better have even fewer shots available, and the services are what help us and our daughter go into the hole.

This metaphor created by parents provides an interesting change in perspective. If each child has the support at their disposal that they need to be able to develop their skills, then there is less distinction between children with disabilities and non-disabled children. Thus the personalized project does not become an opportunity only for children who have difficulties, but is also a useful tool for enhancing the capabilities of each child:

We went to the school and we talked about our daughter, but we have just one regret. We wonder why all parents cannot be given the time to introduce their child, it would certainly be simpler, because it is not only the child with a disability who needs to be introduced.

This example shows how a specific attitude born for a specific need can be really useful to all other children. It is interesting that the school is beginning to consider the possibility of building a school environment responsive to the needs of all children. The school, therefore, can provide an environment that enhances the educational paths of all students, regardless of disability.

Conclusion and implications

The research highlights significant experiences that were shared by most of the families. The first point is that diagnosis is seen as a 'Station of the Cross' and can be summarized with the sentence: 'There is something wrong, but what?' and relates to the way in which the diagnosis is communicated. Sometimes the diagnosis is clear, while at other times it comes after a long ordeal comprising visits to specialists and frequent frustration. Concern for their children's health often comes with the added feeling of not being understood and of being isolated, as if the alliance between the doctor and family is a kind of struggle.

The diagnosis, then, becomes a new starting point. The family seeks other opinions, specialists require more tests, and the 'Station of the Cross' seems to have no end. Even when the name of the disability is known, every day the parents discover 'a little' more about the impact that the disability will have on the child's quality of life, and on the whole family. At this stage, the communication of the diagnosis in itself is crucial, but even more crucial are the methods used by specialists, as well as the attention given to the experiences of family members. The specialists should not carry out their work without taking parents' feelings into account.

Yet, doctors often ask questions without offering explanations to parents, which increases their anxiety. Instead parents should be given reasons for asking questions, making sure that the parents understand the specialists' rationale, and explaining what actions they (i.e. the specialists) intend to take. By increasing the parents' level of involvement, parents are empowered and feel that they are better equipped to help their children.

When the child starts school, the diagnosis can be a wall, can be an obstacle in the child's experience of school. Parents discover information about their child on a daily basis through contact with other people, and as in everyday life, by identifying the best interventions to support their child. They experience comparison with other 'normal' adults and children, which becomes inevitable when the child starts school. This can be summarized with the following question: 'What relationship can there be between my child and the so-called normality implicit in society?' It is a comparison that is made up of words, gestures, and looks.

Society defines the regulations that guarantee the protection of the rights of children with disabilities and their families through the presence of support teachers and an individualized program. By families this can be regarded as an obstacle or as an opportunity for them and for their children.

When parents do not feel involved and see the presence of the support teacher as something that is imposed on them, it is easier for them to feel discriminated against and therefore to demand 'normal' treatment for their children. This means that it is not sufficient to provide laws and support services for families. They need to be involved directly and to be considered as being equipped to help children. Parents need to be prepared and cannot merely be considered the recipients of their children's projects. They need to be able to choose and construct these programs, with the support and collaboration of teachers.

This is why this relationship of trust and cooperation cannot be taken for granted from the outset, but must be the result of a process shared by all those involved in the child's growth. When this does not happen, parents experience a kind of additional labelling, which can lead to additional suffering. This is even more significant when respondents underline the difficulties that can arise from the relationship with other parents. This aspect describes the social dimension of disability well, which goes beyond the condition and focuses on the interactions that the child (and his/her family) experiences with other members of society. If it is true that relationships can be difficult, and thus somehow disabling for the family, then it is conceivable that society can also act in an enabling manner, and can provide that support for the family. The attitudes that seem to favour this value the skills that parents have to help their children grow, and also trust and collaboration with teachers, sharing information, and the willingness to recognize and capitalize on the child's potential skills, beyond the disability.

Some parents have asked themselves: 'Is it only disabled children (and, more generally, people with disabilities) who have special needs?'. If the answer is 'yes', then disability is considered an experience that only affects a few unfortunate people and the family must merely be helped to process the tragedy. This definition reflects medical disability, which calls for the intervention of doctors and involves only a few people certified by a diagnosis. However, if the answer is 'no', then the disability can be seen as a difficulty that is not exclusive to children who have been diagnosed as having a disability, but can involve all children. The disability, in its social definition, is a barrier created by the environment that can be removed by society intervening (in this case within the school). It is no longer a problem that affects a few children, but it can cover all children and, above all, it can be overcome thanks to social intervention. This then provides the opportunity to build interventions through parent-teacher cooperation. If interventions are open to all children, then each child (and their family) should also be involved. This means that the actors involved are all children, their families, and teachers. Returning to the metaphor of golf, we can say that thanks to cooperation between children, family, and school; each child can be put in a position of being able to reach the hole with the fewest number of strokes; and has all the support they need to move forward in their lives.

This research highlights some operational implications needed to try to establish effective integration programs. Firstly, the time of diagnosis is definitely a critical time for parents, who must be supported in terms of managing their emotions; they should be properly informed not only about their children's limits, but also about their potential. They must also accompany their child's acceptance and should be considered capable of and a driving force behind decisions that affect their children. If parents are helped to imagine a positive future for their children and are considered able to help their children, the diagnosis will acquire more positive connotations.

Secondly, disability is not a medical issue but a social question; diagnosis is the tool that allows children to have personalized support in schools but should not negatively affect their chances. Thanks to this form of support being offered, children can access the services that allow them to overcome barriers that would deny them the full range of their rights within school. The communication of the diagnosis to parents and the experience that they have in relation to the doctors also becomes a defining moment in terms of the attitude that parents have when the child enters the world of school. Furthermore, only through networking – which includes the involvement of all children, parents, and teachers – is it possible to support children in building routes that can enhance their potential.

Finally, if the focus of the school is on the characteristics and potential of each child, it is possible to overcome the distinction between children with disabilities and their classmates. What is

highlighted is not the disability but the potential of the child in his uniqueness. In this way, disability is no longer the dominant aspect, but becomes only a part of the child's life.

Disclosure statement

No potential conflict of interest was reported by the author.

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