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FAMILY REACTIONS IN THE FACE OF A CHILD IN A SITUATION OF DISABILITY[1]

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ABSTRACT

The purpose of this study was to understand the complexity experienced by the family of children with disabilities from their own point of view. Non-directive and assistance interviews were conducted with six mothers of children with disabilities who described their life histories. From the reports, the discussion on different topics was constructed and in this text we will deal specifically with the family reactions to the birth of a child with a disability in the family. To deny, to reject, to find a culprit for the situation, to take refuge in their suffering are some perfectly possible reactions in the parents of children with disabilities. However, the search for balance and the referral of the issues of being deviant tend to arise over time and the child in a disability situation is almost always incorporated into the family dynamics.

KEYWORDS

Family. Deficiency. Life's history.

REAÇÕES FAMILIARES DIANTE DA CRIANÇA EM SITUAÇÃO DE DEFICIÊNCIA

RESUMO

Este estudo teve por finalidade apreender a complexidade vivida pela família da criança em situação de deficiência a partir do seu próprio ponto de vista. Foram realizadas entrevistas na linha não diretiva e de ajuda com seis mães de crianças em situação de deficiência, as quais descreveram suas histórias de vida. A partir dos relatos, construiu-se a discussão sobre diferentes tópicos, tratando-se especificamente neste texto das reações familiares diante do nascimento de uma criança em situação de deficiência na família. Negar, rejeitar, buscar um culpado para a situação, refugiar-se no seu sofrimento são algumas reações perfeitamente possíveis nos pais de crianças em situação de deficiência. Todavia, a busca do equilíbrio e o encaminhamento das questões afetas ao ser desviante tendem a surgir com o tempo e o filho em situação de deficiência é quase sempre incorporado à dinâmica familiar.

PALAVRAS-CHAVE

Família. Deficiência. História de vida.

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[1] Article produced from the master's dissertation by Marques (1992).

REACCIONES FAMILIARES DIANTE DEL NIÑO EN SITUACIÓN DE DEFICIENCIA

RESUMEN
Este estudio tuvo por finalidad aprehender la complejidad vivida por la familia del niño en situación de discapacidad desde su propio punto de vista. Se realizaron entrevistas en la línea no directiva y de ayuda con seis madres de niños en situación de discapacidad, que describieron sus historias de vida. A partir de los relatos, se construyó la discusión sobre diferentes tópicos. En este texto, se tratará específicamente de las reacciones familiares ante el nacimiento de un niño en situación de deficiencia en la familia. Negar, rechazar, buscar a un culpable para la situación, refugiarse en su sufrimiento son algunas reacciones perfectamente posibles en los padres de niños en situación de discapacidad. Sin embargo, la búsqueda del equilibrio y la resolución de problemas que afectan la desviación tienden a surgir con el tiempo y el niño discapacitado casi siempre se incorpora a la dinámica familiar.

PALABRAS CLAVE
Familia. Discapacidad. Historia de vida.

1 PROPOSAL AND INTENTIONS

When I decided to investigate the issues experienced by families of people with disabilities, I had a clear perception that the daily difficulties these families faced were huge and greatly diverse. My theoretical knowledge concerning this complexity assured me, a priori, of the extent of embarrassing situations to which people with disabilities and their families and close friends are subjected.

However, the reader's experiential world is extremely limited in the face of real life's complexity, even if authors arduously strive to convey the content of their messages as accurate to reality as possible. The message is inevitably filtered, being presented in isolated facets or aspects that try, in the best possible way, to reconstruct the entirety of facts.

The importance and abundance of informative texts notwithstanding, I consider direct contact with the actual experience subjects indispensable, in this case, mothers of children with congenital disabilities, whose everyday life details are hard to convey through a few written words.

By carrying out this research, I was able to experience the drama of each mother I interviewed. Their speeches, often evocative of distant facts, were always charged with strong emotions, as though they were reincarnating their old, but still alive, roles as hurt, distressed and fearful people facing uncertainty and the dearth of personal and social horizons, both for themselves and their “deviant” children.

I do not intend, however, to measure these people’s pain, since only those who feel it are allowed to measure their own pain. My purpose was, first and foremost, to create a moment in which these mothers could express, in their own way, how it was and how it is to have a child who was discovered to have a disability at birth. The angle of approach was always that of the interviewee, which, in my opinion, provided an atmosphere favorable to venting, as though they were letting out a scream that was trapped in their throats. Thus, I can now assert that the moment was necessary not only for me to listen, but also for them to speak. Surely the established relationship wasn’t limited to simple data collection, but could actually evolve into an assistance relationship, in which everyone experienced growth, both interviewees and interviewer.

My visits to people’s houses allowed me to move beyond simple life history reports. I could, in fact, get to know each family’s lifestyle, the kinds of relationships that existed among their members, and the paths found by each family group to live with the stigma of disability and their respective efforts to balance it.

2 METHODOLOGICAL PATHS AND SUBJECTS

My intention was to use life history as methodological support in this research, where each subject’s speech – with their individuality and specificity –, after being constructed, was broken down, reassembled, and interpreted, being diluted in the social fabric that integrates the subject group.

The life history method allows a dialogue with the research subjects, in which they build their own categories, enabling us to see other dimensions and to think more creatively about the issue that we intend to analyze. This entails overcoming the implicit violence in procedures that involve the imposition of categories that don’t concern the subjects, deriving from a theory that is foreign to them or from the researcher’s own values. It is expected, thus, that based on life histories, on the concrete experience of specific situations, we can restructure assumptions and hypotheses about the issue studied.

According to Queiroz (1987, p. 275, our translation), the life history:

> […] is defined as a narrator's report about their own existence throughout time, trying to reconstitute the events they lived and convey the experience they gained. Linear and individual narrative of the events they consider significant, through which they outline their relationship with members from their group, their profession, their social level, their global society, being up to the researcher to unravel them.

The researcher's interest in this kind of research is in capturing something that surmounts the individual character of what is conveyed and that inserts itself in the communities to which the narrator belongs. Life histories matter not as individual histories, but insofar as they show a social universe. Through the narrator's eyes, they are not who the researcher intends to see, but rather their world. Life histories capture, therefore, what happens in the intersection of individual and social life.

Another important aspect that can be highlighted is that, in life histories, although the narrator decides what to narrate, it is up to the researcher to define the research theme and to devise the issues to be elucidated, proposing questions. Thus, the report itself contains what the narration subject decided to offer.

Life histories are also marked by forward and backward movements, and the researcher shouldn't interfere in order to establish chronologies, since these time variations can constitute indications of something that will allow the formulation of inferences.

This research's subjects were six families of children with disabilities, collecting the life histories with the mothers of people with intellectual, visual and physical disabilities, all congenital and discovered at the children's births, with a total of six reports, equally distributed among the three disability categories.

Due to ethical issues, I committed not to disclose the identity of families involved in the research, choosing to identify them using the first names of famous personalities with disabilities: Christopher[2], Loretta[3], Ray[4], Helen[5], Stephen[6] and Frida[7].

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[2] Christopher Joseph Burke was born on August 26, 1965, in Point Lookout, New York. He has Down syndrome and is an American actor.

[3] Loretta Claiborne was born in New York, Pennsylvania, in 1953. She has an intellectual disability and low vision and did not walk or speak until she was 4 years old. She became one of the best athletes in the history of Special Olympics.

[4] Ray Charles was born on September 23, 1930, in Albany and died on June 10, 2004, in Los Angeles. He went completely blind when he was 7 years old. He was an American pianist and singer, pioneer in soul,

Likewise, I omitted any mentions to names of institutions, streets, neighborhoods, cities and professionals that might help in identifying the research subjects or compromise professional ethics. The reports were constructed with mothers due to the fact that, usually, they are closer to their respective children.

An important piece of information is the fact that I worked only with people with congenital disabilities, i.e., those developed before birth, since one of the issues studied in the research is the complexity experienced by the disabled child's family who recognize the situation from the moment of birth. This justifies not including in the research cases of special needs that are hard to detect at birth, such as giftedness/high ability, deafness, speech impairment and global developmental disorders. Likewise, cases of multiple disabilities weren't considered based on the fact that they are commonly characterized, at first, as cases of primary disability, usually the most evident one when the child is born.

The interview was used as research tool, which, according to Ludke and André (1986), represents, next to observation, one of the basic tools of data collection within a qualitative research approach. The modality used was the unstructured interview, characterized by being non-directive, fostering greater interaction between researcher and subject, creating an atmosphere of reciprocal influence between them. Here, there isn't the imposition of a strict question order, since there isn't an interview script. The interviewee talks freely, prompted by proposed thematic references, defining at will the field to explore, without submitting to a predetermined structure. Functionally, this interview has the great advantage of allowing immediate and current gathering of desired information, with practically any kind of informant. Likewise, it also allows corrections, clarifications and adaptations during its development, in direct contact with the subject.

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blues and jazz music, helping to define its format in the end of the 1950s, besides being an innovative R&B interpreter.

[5] Helen Adams Keller was born on June 27, 1880, in Tuscumia, Alabama, and died on June 1st, 1968, in Westport, Connecticut. She had deafblindness. She was an American writer, lecturer and social activist.

[6] Stephen Hawking was born on January 8, 1942, and died on March 14, 2018. He was a famous British theoretical physicist whose career lasted over 40 years. His body was affected by a neurological disease called amyotrophic lateral sclerosis.

[7] Frida Kahlo was born in Coyoacán village, in Mexico, on July 6, 1907, and died in Coyoacán, in Mexico, on July 13, 1954. A renowned Mexican painter who mostly painted portraits. All of her work is colorful and has impressive intensity. She had polio at the age of six, which caused her left leg to be much thinner than her right leg.

In further discussion of this theme, Thiollent (1982, p. 85, our translation) states that:

> The depth allowed by non-directiveness, along with its ability to 'facilitate the production of meanings strongly charged with affection, even when presented as stereotypes: what we seek to bring to light, in fact, is the underlying logic in associations that, after the initial instruction, will lead the interviewee to approach this or that theme, backtrack, or move on to other themes'.

The objective of the non-directive interview consists of apprehending the identifications through the subjects' speech, by overcoming the reproaches manifested in them. This enables the understanding of the phenomena in their social and individual dimensions.

In order to go beyond simple data collection with the research subjects, I also chose to confer to the non-directive interview the aspect of an assistance interview, as proposed by Benjamin (1985) by highlighting the relationship function, emphasizing the subject's growth process, concurrently with the supplying of information. According to Benjamin (1985, p. 14, our translation):

> Assisting, an empowerment act. The interviewer empowers the interviewee to recognize, feel, know, decide, choose if they must change. […] The assistance interview, the broad verbal interaction between interviewer and interviewee, in which the empowerment act takes place.

From a structural point of view, the interview, according to the same author, has three moments, which aren't always clearly discernible. The first moment consists of the opening or designation of the problem, when the issue that motivated the meeting is situated, ending when both the interviewer and the interviewee understand what should be discussed and agree to do so. The development or exploration phase, which constitutes the second moment, is characterized by mutual examination of the issue, with the interviewer showing interest in the interviewee's internal reference frame, rather than in what is central for themselves. Finally, the third moment represents closure, which should happen through the acknowledgement and acceptance, by both interviewer and interviewee, of the occurrence of the moment.

Hereby, it was possible to advance coherently and safely the research, always intending to study the issue in greater depth and having, as reference, the life histories of the research subjects, a priori without the pretension of confirming or imposing theoretical assumptions concerning the issue.

3 FAMILY REACTIONS AND DISABILITY

Since it is a very complex and problematic situation for the family and especially the mother, the birth of a child with disability can trigger a series of reactive behaviors, in an attempt to adapt to the uncomfortable situation that is usually established in the family core. Although there are almost as many different reactions to the existence of a child with disability as there are parents of such children, some kinds of reactions are common enough to justify several authors' attempts to describe such behaviors.

Telford and Sawrey (1976) emphasize the following patterns as the most frequent reactions to the arrival of a child with disability in a family: facing the issue realistically; denial of the disability reality; parents grieving and commiserating their own luck; ambivalence or rejection toward the child; projection of difficulty as a cause of disability; feelings of guilt, shame and depression; and patterns of mutual dependency.

Facing the child's problems realistically – There are parents who are capable of facing realistically and comprehensively the problems posed by the presence of a child with disability, in the same way they face other crises and tensions in their lives.

> *We have to correct. I can't let her do whatever she wants because she has a problem, right? Because, as a mother, I am the only one here she respects.* (Loretta's family, our translation).
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> *As to that, it's not a problem, dear. She's my daughter. […] I talked to her (the school employee): 'She's my daughter, it is my obligation to carry her'. So, I always treat her just like the others, normally. If she talks back, she needs discipline. Just because she's like that doesn't mean she won't be disciplined, I won't tell her off, you know? I always have to tell her off.* (Frida's family, our translation).

Denial of the child's disability – Most parents react to the existence of a disability in one of their children with denial. There are several social and personal factors that motivate this denial, such as the cultural stereotype of the ideal child, parents' expectations that their children will successfully perform the roles attributed to them by society and the parents themselves, the hope that their children will meet or exceed the parents' own achievements.

> *Then, a doctor said, when I went to pick him up, that he had no other problems, everything was fine with him, but he had a vision problem, he couldn't see and that's with he didn't do some things. […] His father, when I got home and told him, said to me: 'The doctors are crazy. That doctor doesn't know anything. You'll see. He'll come home, we'll take him to another doctor and he won't say any of that'.I started crying and he said: 'Oh, no. Don't cry. That's silly. Doctors make mistakes. He'll be fine'.* (Ray's family, our translation).

Self-commiseration – Some parents experience feelings of self-pity and commiseration of their own luck when faced with the existence of a child with a disability.

> *[…] And I feel really alone with that, you know? Because I live for her and she, like, she doesn't live for me, because I have no payback. So some days I think: 'Oh, gosh, if my daughter were a normal person, our life could be so different!'.* (Loretta's family, our translation).

Ambivalent feelings toward the disabled person – At the same time that they accept and love their children, parents also reject and detest them. These ambivalent feelings give rise to guilty reactions that, in turn, result in overprotection, excessive care and constant suffering in the parents. Concerning treatment for the child with a disability, parents feel torn between preventing realistically needed care and assistance, on one hand, and excessive care, feeding into impotence and excessive dependence, on the other hand. "*His father did not accept his disability at all. And because he didn't accept it, he spoiled him*" (Ray's family, our translation).

Projection – It happens when parents, trying to defend themselves from their own anxiety, blame others for the discomfort caused by the child's disability. Distressed parents frequently project the causes of the child's disability onto their other children, their spouse, doctors, teachers, therapists, or even society as a whole. "Also, because the father accused me. […] Because then he accused me and I accused him" (Loretta's family, our translation).

Guilt, shame and depression – Shame is usually alter-oriented, involving the expectation of ridicule or criticism from other. Guilt is usually ego-oriented, entailing self-censorship, remorse, and a feeling of personal depreciation. Both feelings result in a high degree of anxiety. Depression arises from the association of the feeling of guilt, or selfrecrimination, with anxiety and personal depreciation. On the other hand, the association of shame and anxiety can protect the concept of self, directing hostility externally.

> *I was really worried about the cause of the problem. Because before I got pregnant with her, I used drugs, you know? So, I thought, like, it could be a consequence. […] So, my fear when the girl was born was that. […] I immediately felt guilty.* (Loretta's family, our translation).

Mutual dependence patterns – Usually, the child with a disability has a relationship of dependence with the parents. Some parents, however, also become dependent on the child with a disability. This happens when one of the parents (or both) invests a large part of their life in assisting the child with a disability. With feedback, this mutual dependence can be perpetuated, constituting a neurotic relationship.

> *I know someone, there's a sister of a friend who's in bed. Never walked. She's 38 years old. Her mother is so frail, just a wisp of a person, really frail, you know? But she's alive, taking care of the daughter to this day. And he always says: 'Mom, the second you die, she dies. The second she dies, you die, you know?'. The connection is too deep. Like I said, my daughter won't sleep if I'm not there. Won't sleep, won't eat. She doesn't accept another person feeding her. She eats, like, she makes a mess, doesn't sit still at the table, you know? So, like, it's gonna be very hard, you see? It's gonna be so very hard.* (Loretta's family, our translation).

Concerned with describing the possible reactions of parents of children with disabilities, Telford and Sawrey (1976) didn't establish any connections between the reactions, approaching them independently and without a dynamic view in terms of phases or steps in a bigger process of conflict and attempts to overcome the crisis installed by the birth of a malformed infant. In contrast, Moura (s.d.) systematizes in phases the passage through the process of elaboration of conflicts caused by the crisis.

1st phase: Denial – Denying reality arises as an attempt to create a protective shield against the intense pain caused by initial shock. This denial can also manifest itself in the form of indifference, apathy or manic denial, with superfluous concerns or through exaggerated movement and speech.

> *It was a fight for survival. This period doesn't even count, we didn't read anything, we had no information. It was just a heart problem. Delay… There was no delay. I had no idea about Down characteristics, nothing, I didn't see. I wasn't interested, because it was here and now, and that was it.* (Christopher's family, our translation).

> *I got home, after a week, more or less. I talked to my husband, like: 'This girl can't see'. He almost died. He was taken aback, said: 'Are you going mad?! God forbid! What do you mean, can't see?'. […] He said: 'Lord! God forbid! You're going crazy'.* (Helen's family, our translation).

2nd phase: Release of impulsive reactions – After the first phase, there is the release of impulsive reactions that are translated into feelings of disappointment, anger, sadness and, frequently, the wish that the child were dead. In this moment, solution suggestions are rarely accepted, because emotion is too intense, taking over all rational space. "*But, when I had him, I had a lot of disappointment*" (Ray's family, our translation).

3rd phase: Search for the culprit – Due to the non-acceptance of the child with a disability and the feeling of guilt that underlies the rejection, there is the need to seek a culprit – the partner, the doctor, each parent's family origins etc. – to relieve the distress. "*Just like my sister-in-law… his sister… sometimes tells him to have our blood tested, that maybe our blood doesn't fit together*" (Frida's family, our translation).

4th phase: Depression – With time, reality asserts itself. Thus, a deep sadness is established, whose expression allows grief to be lived, dreams to be buried, and now other feelings can arise.

> *Sometimes, on days I'm, like, anguished, depressed, I tell them* [friends] *my problem, they say: 'No, the girl is your support. Maybe, if not for her you would be worse'. So that, like, comforts me for a while, you know?* (Loretta's family, our translation).

5th phase: Acceptance – Acceptance happens when the family finds meaning for that child in their lives.

Another important fact, according to Moura (s.d.), is that crystallization can happen in any phase of the process, becoming, thus, pathological. Among other situations, the parents may divorce; or the family may be structured around the child with a disability, who will be the depositary of everyone's disease. "*Because there's a case of a pediatrician in Rio who abandoned, never went back home, when he saw the labor and saw it was Down, he didn't come back, others… and a lot of cases, you know?*" (Christopher's family, our translation).

Farber (apud SILVA, 1988) admits two types of crises, when the child's disability is perceived by the parents as an uncontrollable event. Tragic crisis – Happens when the parents realize they won't be able to accomplish all their dreams and expectations concerning the child. Role disorganization crisis – This crisis entails a disruption in the family life cycle.

The same author denominates as adaptation the process of adjustment to the condition that caused the crisis. This phenomenon happens through modifications in the roles and rules of each family member, or in the family interaction undertaken by them, individually or collectively, in order to effectively handle the problematic situation, whether to solve it or to live with it.

According to Wolfensberger (apud SILVA, 1988), there can be three types of crisis subsequent to the moment in which the child's disability is discovered. Crisis of shocking news – This crisis is installed when parents are surprised by the arrival of a child with a disability, resulting in the frustration of expectations they had concerning the child's future. "*Then, we were over that silence, fright, phase, you know? That we went through, that kind of obscure thing really*" (Christopher's family, our translation); "*If we had been prepared… it would be easier to accept*" (Stephen's family, our translation).

Personal values crisis – Consists in the parents' reactions when faced with the child's disability and its manifestations, deemed unacceptable in their values system. "*When he* [the father] *picked up the kids to take them out, he only wanted to take the girl, and I told him to take the boy too*" (Stephen's family, our translation).

Reality crisis – This crisis stems from circumstances that demand from parents constant care that exceed their personal abilities, such as intensive physical care demanded by the child, hyperactivity or some dangerous behavior they may display, which makes daily life with the child exhaustive.

> *Because I'm not ashamed of her, you understand? Sometimes, I get angry at her, but I leave for school with her in the morning, she pees her clothes, I get angry at her and all, but it's not, like, out of shame. It's because I don't have it in me, you know? Ten years old, like, and I'm fighting with her. […] But I miss, like, because she can't speak, you know? So, sometimes, the day I'm angry, I say: 'Yeah, I'm not a mom, I'm a jerk, aren't I?'. So, there are days when you get real. Not, like, that I try to bury my head in the sand, it's not that. But some days you're more fragile, more sensitive, you know?* (Loretta's family, our translation).
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> *Since she was little, I started teaching everything. Oh, but it's double the work! Hinges a lot on the mother, sure. The work a disabled child takes…*

> *Lord… it's sad. It's not the same as a normal child.* (Helen's family, our translation).
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> *Before she defecated seven times a day. You had just changed her clothes, when you got to the kitchen, there she was: 'Let mom see'. 'It's nothing, mom, it's nothing'. She was afraid to tell, you see? Until, like, 8 or 9 years old, she did that. I looked: 'Oh my God! This girl is dirty again. Sometimes, during the cold months, there were no pants left for her to wear. I got her… got angry with her… bathed her… yelled at her… put her there and went back'.* (Frida's family, our translation).

Based on her experience of many years accompanying more than 350 children with Down syndrome and their families, Lefèvre (1985) observed that the birth of a child with a disability awakens different reactions in their family members. In the first days, there is disbelief. Along the first months, confusion, uncertainty and even hostility toward the world can be noticed. With time, hope appears and interest for the child is developed. As the child starts to talk, walk, and learns to do some things by themselves, a certain tranquility concerning the problem arises. However, in the face of surprise and/or insecurity that appear when new problems are outlined, aggressiveness or stubbornness can arise.

For Martins (apud SILVA, 1988), the birth of a child with a disability almost always leads parents to emotional trauma, leading them to despair, with mutual accusations of blame and heredity, which doesn't enable logical thinking in order to face the problem and fight for the child's recovery.

All the possible reactions triggered by the birth of a child with a disability are relativized by the parents' previous experiences and the concepts of humanity and life that they have at that moment. In any case, overcoming the suffering always culminates in an attitude of inclusion of the child's disability into the family dynamics. According to Silva (1988), the parents can develop two distinct behaviors: accept or assume the imposed disability. For her, accepting results in the fact that the person no longer feels unhappy, diminished or different for having a child with a disability, results in no longer rebelling in the search for the cause of the child's disability and not being angry with "normal" people or those with "normal" children. Assuming, in turn, entails making the decision to do whatever is necessary to approach the child's problem. However, assuming does not entail partial or complete acceptance of the problem and/or of the affected child. Silva (1988) highlights that what is commonly called acceptance is actually assuming the problem. That is, parents stop having “magical thoughts” and start to face the problems related to the child’s disability reflexively and realistically, seeking resources and/or treatment and participating in intervention strategies with the child.

It is important to stress that by accepting or assuming the child’s disability, parents are putting themselves in a position to face the problem, at the same time that they avoid the attitudes of rejecting or overprotecting the child. Otherwise, parents become inadequate agents in the assistance of the child with a disability, which exposes the child to even more reduced stimulation, resulting in even slower development.

4 QUESTIONS AND POSSIBILITIES

It is also important to highlight that the reactions explored in this research aren’t, in any way, exclusive to mothers of children with disabilities. Even mothers of abled children live with the anxiety of labor, develop different reactions to the real child, worry about their educational, professional and emotional future, suffer and delight in their failures and successes. However, all these natural situations may be, and certainly are, exacerbated with the inclusion of a new fact: the child’s significant deviation from the socially conceived and accepted normality curve.

For not complying with the family’s dreams, especially the mother’s dreams, the real child causes a complete turnaround in the initial plans of those who expected them. From the moment the disability is discovered, there are questions and the search for possible solutions. From the ruins of crumbling dreams, the foundation of the new family must be built, even if in this search there are ideas and feelings of death (MANNONI, 1988).

Denying, rejecting, searching a culprit in the situation, taking refuge in suffering (which feels like the biggest ever) are some perfectly possible reactions in parents of children with disabilities. However, seeking balance and carrying out issues concerning the deviant being tend to happen with time, and the child with a disability is almost always integrated into the family dynamics, which is strongly influenced by the new situation. However, there is the possibility that the family isn’t able to restructure, which may lead to a more serious pathology, where the child’s disability encourages directly and/or indirectly the disease of other family members.

It is fundamentally important that we seek to lessen the impact of the news that a child with a disability was born, through adequate intervention by doctors, nurses and psychologists with parents, developing clear diagnoses and prognoses, emphasizing the child's possibilities and respecting, above all, the suffering and distress of the parents, especially the mother. In order to go through the grieving process, it is necessary that parents acknowledge and experience all their emotions, needing people who allow them to grieve and recognize them as people, and not only as parents of a child with a disability.

An important source of support for parents of children with disabilities is the relationship with other parents in the same situation. Thus, it is necessary to create spaces that enable that activity, so that some learn from the experiences of others.

Another urgent measure is the distribution of theoretical and practical information concerning the issues experienced by people with disabilities in our society. Certainly, the safest and easiest path would be to immediately include specific subjects in the curricula of every course, in every teaching level. This would definitely be the first and most decisive step toward a change in people's mindset and attitudes concerning acceptance and respect toward disabled people.

All these measures, collectively, aim to attack the greatest and most central problem faced by people with disabilities: social segregation.

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