Ricerche di Pedagogia e Didattica – Journal of Theories and Research in Education 11, 3 (2016).

Living with disability.
Taking care of siblings

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(Submitted 14/03/2016; published 1/12/2016)

Abstract

La nascita di un bambino disabile rappresenta un evento critico che pone tutti i componenti della famiglia di fronte ad una situazione di forte vulnerabilità. Quando si parla di una famiglia con un figlio disabile, solitamente, l'attenzione viene rivolta ai genitori; mentre ai fratelli viene riservato un ruolo marginale, come dimostrato dalla letteratura di riferimento, in questo circoscritto ambito di indagine. Comunicare la diagnosi anche ai fratelli significa coinvolgerli nel processo di cambiamento familiare per renderli protagonisti e non "spettatori" della propria "nicchia esistenziale". La comunicazione della diagnosi è un processo continuo e delicato, che necessita di avviarsi in maniera adeguata, utilizzando parole e azioni educative mirate. I fratelli vanno aiutati ad accogliere il fratello con disabilità con le sue caratteristiche (comprendenti anche il deficit), attraverso un approccio bilanciato e ponderato che contempli sia la dimensione co-evolutiva che la presa d'atto delle situazioni problematiche.

The birth of a disabled child is a critical event that places all the members of the family in a condition of great vulnerability. When talking about families with a disabled child, attention is usually focused on the parents. Siblings tend to play a marginal role, as shown in the referred literature, in this specific field of investigation. Communicating diagnosis to siblings means involving them in the process of family change, making them active players rather than "spectators" in their own "existential niche". Communication of diagnosis is a delicate, continuous process that has to be tackled appropriately, using targeted words and educational actions. Children need help in accepting and welcoming their disabled sibling, with all his/her characteristics (and deficits), through a balanced, pondered approach that includes both the dimension of co-development and the acknowledgement of problematic situations.

Parole chiave: fratria, cura, disabilità, educazione
Keywords: phratry, care, disability, education

Introduction

In families that have experienced a critical event such as the birth of a child with disabilities, it can be seen how – through a cognitive process – people tend to forget some elements of their past. Their life story is fragmented, with *voids,* without a clear sequence of time and space. Although some defence mechanisms – refusal, denial, removal – may offer a protective function, it is equally necessary to support the people involved (mother, father, siblings) to help them to gradually integrate the painful experience into their own personal history, and that of their family.

Chaltiel and Romano (2007) state that in families experiencing a critical event, a shared family history must be *reconstructed* (to allow the family members to feel united and participate together), from which they may then be freed and differentiate themselves. Only once they have found their own *space* within the family can they then find another space beyond it, and embark on a process of emancipation towards autonomy. The authors also state that in order to start this journey towards self-affirmation, family members have to have reconstructed those *voids* which can create emotional dependencies, slowing the path of growth, causing a sensation of getting lost in one's own history and the impossibility of “moving forwards”.

Retracing one's own life history in order to reconstruct the *voids* allows us to strengthen our own existence in the world. In the life histories of the siblings of people with disabilities, starting from the *communication of diagnosis* means placing the initial moment of information in context, giving it meaning. This is the moment in which people are informed of an event that is very difficult to process, and can indeed create an emotional *void* (and perhaps more besides) that needs to be listened to and understood.

The process of *accompaniment* of the family starts from the communication of diagnosis (Caldin & Serra, 2011): communication of diagnosis is therefore a crucial moment in the construction of a life project for the family (Cfr. *Linee Guida Multidisciplinari per l'Assistenza Integrata alle Persone con Sindrome di Down e alle loro Famiglie. La comunicazione della diagnosi*).

It is based on these assumptions that the research work "Essere fratelli, vivere la disabilità" ("*Being siblings, living with disability*") aims to understand the point of view of siblings of people with disabilities. This work focuses our attention on the communication of diagnosis to siblings, investigating the communication and information methods adopted by parents concerning the state of health of the disabled sibling. The siblings were asked to offer their testimonials – a "reflected past" (Cyrulnik, 2001) – of the first information they were given when their disabled brother or sister was born. Aiming to draft some indications which, in terms of life project, can help to improve the methods used to communicate a diagnosis, and the process of *accompanying the family* (Canevaro, 2006, p. 107).

Sibling in the literature

When talking about families with a disabled child, attention is usually focused on the parents; siblings tend to play a marginal role, as shown in the referred literature, in this specific field of investigation.

Concerning studies on phratry and disability, until the 1980s literature privileged a psycho- pathological interpretation of this relationship. From the 1990s, on the other hand, and particularly in the last decade, we have seen a change in perspective in studying the sibling relationship. From the 1990s, some research works (Furman, 1993; Stoneman & Brody, 1993) began to report that the siblings of disabled children may have completely normal cognitive and emotional development, similar to that of their peers, and may enjoy a good quality of life. These studies have sought to investigate those factors that help to understand how sibling dynamics work; as Valtolina also stated (2004), sibling relationships with a disabled sibling are not automatically negative and/or pathogenic.

More recent studies (Fleary & Heffer, 2013; Iraite & Ibrarrolla-Garcia, 2010; Dykens, 2006; Voizot, 2003) show that to support and accompany the siblings of disabled children in their life paths we have to adopt a *balanced* and *pondered* view which include also the perspective of study based on the *resilience approach* (Malaguti, 2012; Scelles, 2008; Gardou, 2005; Cyrulnik, 2001). Avoiding the risk of both solely emphasising the negative effects and emotions of the disability (as many research works have done) and underlining the positive effects and benefits that this experience can bring (McMillan, 2005; Conners & Stalker, 2003).

The most common question asked by parents of a disabled child, whether the disability was from birth or occurred later, is *why* it happened. We may often think that this question is a part of the exclusive realm of parental thought, but in fact as several studies underline (Shivers *et al.*, 2012), this question is also posed by the other children, whatever their gender and birth order in the family.

The birth of a disabled child is a critical event that places all the members of the family in a condition of great vulnerability. Siblings are those who most suffer in the "family game", understood as the set of– aware or unaware – rules, behaviours and roles through which the members of the family are mutually influenced in the presence of a disabled child (Sidoli, 2002).

While we are familiar with the defence mechanisms (Dykens, 2006; Trisciuzzi, Fratini & Galanti, 1998) that parents of a disabled child may activate following the communication of diagnosis, as well as the various stages the mothers and fathers pass through following the loss of the imagined child. We know very little of the reactions and impact that such communication can have on the siblings.

Zanobini and collaborators (2002) stated that families with disabled children run the risk of experiencing forms of isolation. The authors consider that there is a so-called "critical period" in which the family's support network tends to weaken, consequently losing important resources for the well-being of the family itself. Siblings run an even greater risk of being neglected, as – in most cases – they do not have the internal resources and a support network that existed before the birth of the disabled brother or sister.

In almost all cases, the emotional experiences, doubts and difficulties of siblings remain unexpressed, as they find no spaces either in the family or in any other place, generating uncertainties which – as time passes – can amplify distorted images and contrasting emotions in the child and the adolescent. The emotions felt by siblings towards their disabled brother or sister run from love to protection to empathy to pride, as well as jealousy, guilt, shame and anger (Martinelli, Majorano & Corsano, 2008). Sibling sentiments vary according to age (individual life cycle), the historical moment of the family (family life cycle) and the level of psychological and emotional development reached.

While for the parents there are various forms of support to parenthood (Pourtois & Desmet, 2009; Milani, 2001; Tortello & Pavone 1999). For siblings, on the other hand, the educational actions dedicated specifically to them, which we may define as actions of accompaniment in educational models demanding specific attention, such as those activated in situations of disability, are very few and far between.

The research methodology

The research "Essere fratelli. Vivere la disabilità" ("Being siblings. Living with disability"), investigates one of the least studied topics in the field of disability, from an educational and pedagogic point of view: the *sibling relationship*. The research refers to the theoretical and conceptual frameworks of inclusive education (D'Alessio, 2011; Ainscow, Booth & Dyson, 2006; Armstrong, 2003; Ainscow &

Booth 1998; Stainback & Stainback, 1990) and is based on the integration of a qualitative and exploratory (I phase) as well as a quantitative (II phase) research methodology.

The initial hypothesis revolves around the importance of supporting an early educational intervention also focusing on the siblings of disabled people, starting from the *communication of diagnosis*. According to our hypothesis, the communication of diagnosis, understood as a continuous process over time, would help disabled siblings to cope better with this new reality, made of fears, difficulties and misunderstandings, with positive repercussions both in terms of their sibling relationships and in the construction of identity of the non-disabled brother or sister.

The research included a preliminary phase of exploration of this subject, followed by a second phase broadening the area of investigation, involving a larger group of siblings of disabled people from all over Italy.

The first phase of research involved a small reference group of 4 brothers and 8 sisters aged between 16 and 45 (Tab. 1).

Table 1. The group of non-disabled siblings (stage I of the research)

Gender	Order Of Birth *(compared to the disabled sibling)*	Age group
Female (8) 67%	Minors (4) 31%	Adolescents (3) 25%
Males (4) 33%	Adults (9) 69%	Young adults (5) 42%
		Young adults (5) 42%

This phase of the research, with an exploratory and qualitative function, involved the use of in- depth interviews. The main objective was to investigate the memories linked to the birth of the disabled sibling, the communication of the diagnosis and the difficulties and needs this generated in the brothers and sisters.

The second phase of the research, on the other hand, investigated how to *accompany* the life project of the siblings and which actions and educational interventions could be useful for guaranteeing this in different life phases, (childhood, adolescence, adulthood). The objective of this phase was to study the main conceptual aspects of communicating diagnosis (in continuity with phase I), and to investigate the sibling relationship in the various phases of the life cycle and the relationship with the parents and the social context. In this phase, a semi-structured questionnaire was delivered to a group of 76 people with disabled siblings (Tab. 2).

As can be seen from table 2, the group of siblings was composed of 61 (80%) females and 15 (20%) males, aged between 19 and 68, which is a very broad range. The largest part of the group consists of "young adults" and "adults", representing 94% of the whole reference group, while only 6% were adolescents. As far as provenance is concerned, 55% stated that they live in Northern Italy, 34% in Central Italy and 11% in Southern Italy and the Islands. The complexity and delicacy of the topics led us to decide not to involve – in both phases – children and/or minors in either phase, preferring a target of adolescents, young adults and adults.

Table 2. The group of non-disabled siblings (stage II of the research)

Gender	Order Of Birth *(compared to the disabled sibling)*	Age group
Female (61) 80%	Younger (25) 32%	Adolescents (5) 6%
Males (15) 20%	Older (51) 68%	Young adults (31) 41%
Total (76) 100%	Twins 0 (0%)	Adult (40) 53%

Concerning the birth order, 32% stated that they were younger than their disabled sibling and 51% on the other hand stated that they were the older sibling. As regards the data concerning the disabled siblings, we can state that this group consists of people aged between 15 and 60. 37.5% are female and 62.5% are male. Concerning the sibling's deficit we can state that 60.9% have Syndrome of Down, 19.2% have a cognitive deficit, 9.3% have some form of autism, 6.6% have a sensory deficit and 4% fall in the "other" group.

What do siblings say?

The process of *accompaniment* is the complex and far from linear path, in which the methodological choices must be dictated by shared practices inspired by professional ethics. The first communication affects the future of the disabled child and that of the people directly involved (Glasberg, 2000). For these reasons it is important to avoid extemporaneous or contradictory communications without any project basis.

Overall, the results of our research show that: 51.6% of the siblings stated that they were informed of the diagnosis, 36.6%, on the other hand, stated that they never received any form of communication and the remaining 11.8% stated that, at the time of completing the questionnaire, they did not remember whether they had (or had not) received any information on their sibling's state of health.

Concerning the group of siblings who stated that they had received “communication of diagnosis”, over half (58.7%) stated that they were not satisfied with the information they had received: the degree of satisfaction lies at a medium-low level, even in those situations in which the parents decided to tackle the issue. Only 8.9% stated that they considered the information – and the methods – in which they had received it following the birth of the disabled sibling as “excellent”, underlining the great efforts made by their parents in managing this very delicate and complex moment.

> I was very grateful to my parents: when G. was born, the word disabled was taboo. It wasn't like now, things have changed. However, my parents were strong and brave, and told me what they had understood from the doctors in Genoa (M.N.).

As we have stated, while the process of *accompaniment* should start with the communication of diagnosis, the siblings must also receive modulated communication suited to their own ability to receive, understand and tolerate the situation. These dimensions represent the key “strengths” noted in their parents' words by those siblings who stated that they were “fully satisfied”.

> My parents never lied to me when I asked them questions; they calmly and clearly explained the whole situation to me, or at least, all that an eight-year-old girl can understand. This brought me closer to my disabled sister (M.N.).

> The first positive factor is that the diagnosis was communicated to me; the second was the “normality” of that communication (R.O.).

> I think the strength [of the communication] was the sincerity and naturalness my mother used when she explained it to me (A.C.).

> I remember the calm and simple language, which was suited to me who was still a child (I.S.).

On the other hand, the group of siblings who stated that they were “fairly or greatly unsatisfied” reported among the “weaknesses” the lack of clarity, the delay with which the diagnosis was communicated, the climate of anxiety in the air and the excessive pessimism over the future. Some parents also gave unclear information to their children, delivered in a hurried, negative and indirect manner that risked hindering their children's ability to relate to the new situation.

> The communication was crude and unexpected (S.T.).
>
> It was extremely traumatic, totally lacking in sensitivity both towards my brother and me. It just made me confused, it made me feel inadequate (M.D.).
>
> The negativity they expressed over the future turned out to be far more positive than they had expected (T.M.).
>
> I would have preferred to have been told beforehand, and not when I asked. After the diagnosis, I understood some of the "strange" behavior and the moments of desperation that came in the days after my sister was born which, at the time, I was unable to interpret (M.U.).
>
> I remember their dour faces, and the way I got the brunt of their stress during that time (P.P.).

Communicating the diagnosis is therefore a fundamental passage for the siblings and a moment that cannot be either neglected or forgotten by the adults involved. Parents certainly have a very delicate task: some communications, such as those linked to the deficit of a child, are always "bad" news, very difficult both to tell and to receive. In this regard, we believe that the intensity of the news can also affect the degree of satisfaction of the recipient: this could partly explain the high percentages of those siblings who stated some disappointment over the communication they received.

> Full efforts need to be made when providing information for the first time, paying the utmost attention […] indeed, for us it is implicit that, however much care we take in giving the first information, it is never enough, and can always cause disorientation. Even this first information, offered with great care and in a context of serenity, can then be a source of disorientation. [The information] needs to have a dimension of process, it must become part of a cultural, mental, personal context and for this reason must not be taken on board as it is given but must be reformulated, reorganized and completed (Canevaro, 2006, p. 108).

Despite the efforts made and the great care taken by many parents when giving information, from the results of the research it can be seen how some parents, on the other hand, tend to hide the truth about the condition of the disabled child from the other children, hoping to protect them from this pain. While other parents are unable to communicate the event to their children because they do not know how to tackle the matter with them, or how to explain the disability of their sibling (Farinella, 2015; Valtolina, 2004).

> I remember that my parents always tried to "pretend" that everything was fine, to protect me (P.R.).

> The diagnosis wasn't clear or easy to understand for my parents either. I acknowledge that they did all they could, even though that was not much, because they too had been left very much alone (S.L.).

> The "explanations" came late, we might say. I had already understood on my own that something was wrong. For instance, by the amount of time I spent at my grandparents' house (C.F.).

To better understand the reactions and impacts the communication of diagnosis can generate, we asked the siblings to indicate the emotions they felt after having talked to their parents about their disabled brother or sister. The experiences with the highest percentages are: a) the need to understand (42.5%), b) sadness (28.2%), c) a sense of bewilderment (23.4%), d) anger (23.4%), e) uncertainty (23.4%), f) fear (21%). It is necessary to talk to the siblings of a disabled child, whatever their age. They must be supported emotionally, accompanied and supported right from the start, as well as in the subsequent phases of their life cycle, such as during adolescence. In larger families (with more children), it may be advisable to provide the first information to all the children together, so as not to overload one sibling with responsibility for protecting others from suffering, thus avoiding an imbalance of responsibility among the siblings. It may then be important to follow up with other moments of discussion with each child, individually devoting them the time needed to allow them to acknowledge the disability (Montuschi, 1997), providing reassurance, dedicating time and space to each sibling.

To assure effective communication, there must be emotional and affective participation, a sense of limit (it is not necessary to "tell everything"), competence, patience, acceptance of emotional reactions (anger, tears, sadness), the ability to support defence mechanisms (denial, refusal, etc.), the ability to listen and perceive that which is not said, to stimulate questions and check that there is understanding by asking exploratory questions (Caldin, 2010; Bellin & Kovacs, 2006).

Another important part of communicating the diagnosis is being able to calibrate the quantity and type of information, tailored to the recipient and their ability to take it in at that moment (Montobbio & Navone, 2003). Explanations must be accompanied by concrete, familiar, clear examples, images and/or drawings. It is important to avoid underlining only the negative aspects linked to the deficit, but also to describe the positive aspects, the potential that will be gradually discovered over the years. It is not always necessary to go into detail, but the important thing is not to fool the children, nor to pretend that there is no problem when it is clear that "something is wrong": information can change the perspectives of fear, uncertainty and anxiety.

It is also fundamental that information not be given only once and only by the parents, but also by an educational or psychological figure (educator, counsellor, psychologist) from outside the family. The person communicating must remember to talk about "that" child, where possible calling them by name while they talk, not referring only to the deficit underlying the diagnosis, which risks compromising the bonds of affection and recognition among siblings.

As for the parents, also for the siblings the understanding of the disability of their brother or sister cannot be resolved in the first communication; the first discussion aims to "give time", starting a process of digestion and understanding, by "accepting the reality, acknowledging the events and the emotions these arouse in us" (Montuschi, 1997, p. 83).

Communicating diagnosis to siblings also means involving them in the process of change that takes place in the family, aiming to make them active players and not merely "spectators" of the intra- family dynamics, so as not to forget them and their needs, fears, expectations, curiosities and so on. The siblings must be helped to welcome their disabled brother or sister and their limits, but also their potentials, even though these may not be immediately visible.

> Communication of diagnosis would have involved me in the family, I would have had a role too, I would not have felt guilty for being "normal" and perhaps I would have been able to enjoy a very different relationship with my sister (L.F.).

In our research, the siblings underline the importance of the first communication as a very important moment for their own life path: 96% of those interviewed stated that they "fully agreed" with the statement "i*t is important to communicate the diagnosis also to brothers and sisters*". And, again, 83% added that they "fully agreed" that "*the ideal situation is when brothers and sisters are also informed*".

It can be seen that we must begin to talk of a specific right to information also for siblings, starting from the communication of the diagnosis and continuing throughout their life (childhood, adolescence and adulthood), in a recurrent manner and gradually over time (Farinella, 2015; Caldin & Cinotti, 2013; Scelles, 2008). That offers space for the doubts, fears and perplexities that may be encountered in all life phases (from childhood to adulthood).

Finally, the siblings reported how communication of diagnosis not only has the function of "communicating the sibling's health condition", but also that the communication itself conveys and brings with it other meanings, also towards the non-disabled sibling, helping to fill those *voids* we spoke of at the start of this work.

In this regard, the questions investigating *why* it is "really" important to communicate the diagnosis to siblings, we can see that the siblings attribute a profound meaning to this moment, also in relation to themselves:

- 71% state that it would be important to make the siblings feel a part of the family;
- 69% state that it would be important to support the siblings right from the start and avoid making them feel alone;
- 61% state that it would be important to avoid making the siblings feel less important.

It would seem that the priority needs of siblings is that their parents *take care* of them too, as growing people with their own needs and times to be respected, day after day. Without careful and appropriate explanations from their referred adults, siblings risk building a distorted image of the disabled brother or sister and, sometimes, a sense of solitude, particularly in childhood, but also – while with different thoughts – in adolescence and adulthood. The feeling of isolation and having nobody to share the experience of having a disabled sibling with represents a void to be filled through *preventive* educational actions. In educational and pedagogic terms, providing appropriate support to the various members of the family means promoting educational actions aiming to transmit culture, competences and knowledge linked to the process of *accompaniment* of the family members involved in the situation of disability. Today more than ever, in educational models demanding particular attention it is fundamental to rethink the meaning of taking care. Taking care must acquire a strongly educational and pedagogical meaning, unbound from all logics of protection and assistance, striving for a long-term life project through educational interventions based on primary prevention and aiming to support family empowerment.

Educational perspectives

This research both hypotheses and identifies *dialogue* – starting from the communication of diagnosis – as one of the most effective ways of starting a process of *accompaniment* for the families, aiming to take care of all persons involved in the life of the disabled person and who may be in a condition or situation of great vulnerability.

In the reflections described above, we have tried to focus our attention on the importance of communicating diagnosis also to siblings, and how some methods of intervention and communication strategies can offer valid responses to the need for information that the siblings describe in their experiences with disability.

Support must necessarily focus on the family as a whole, and not on the individual or the disabled person: focusing the educational actions on the needs of everyone is a fundamental condition in the process of *accompaniment* of families who find themselves in problematic situations.

Sometimes, voids are reported in the services supporting families (including siblings), above all concerning some crucial phases of the life cycle, such as the moment in which the diagnosis is communicated.

When there is a disabled child in a family, the other siblings are only rarely considered by the services (and at times even by the parents) as fully-fledged members of the family. As the parents play a fundamental role in the education of disabled child, siblings also have an important role in the development and growth of their disabled brother or sister.

In the situations described above, the first step is to include the siblings in the process of *accompaniment*, enhancing all the educational actions supporting the siblings. The services - in close partnership with the parents – must *take care* of the siblings, who are also growing people with their own needs to be taken on board and their times to be respected.

In this regard, with a view to preventive education, we believe that a carefully planned educational action must be delivered early on with the siblings (Caldin & Serra, 2011; Del Piccolo, 2007), aiming to foster their involvement in "family life" (also relating to their disabled brother or sister), with positive repercussions on the fraternal relationship and for the general family climate. Our proposal is to enhance projects supporting the post-natal development of the disabled child and all the family, through a *home-based dimension* aiming to: foster the *presence* of the siblings; help both parents to cope with the return home and the first few months, taking care of *all* the children; *support* the siblings in accepting the new reality, also having the possibility to talk about the health conditions of their disabled brother or sister.

Concerning this point, as far as the communication of the diagnosis is concerned, in a home-based dimension, educational interventions that are continuous over time could be activated with the aim of:

- *reconstructing and creating alliances*: creating memory, rebuilding their own life story (and family story) through continuative dialogue in the family; communicating the diagnosis using pro-active, project-based methods; communicating the diagnosis to include the siblings in a global family-life project; developing/initiating collaborations with educational, social and health professionals;
- *informing and training:* ensuring a relationship based on gradual and constant communication (recursiveness); making concrete references using familiar examples; communicating that which is certain and accessible,

without excessively underlining the negative aspects; communicating the diagnosis as soon as possible: not hiding the event; communicating the diagnosis to all siblings, whatever their age; communicating the diagnosis by adapting the information and contents to suit the character and age of the sibling; communicating the diagnosis in a private and preferably familiar environment;

- *welcoming/accepting:* placing each person in relation to the other using empathy, open-mindedness towards dialogue and listening; being able to work to limit psychological suffering and spread hope (Meltzer & Harris, 1986), when tackling an unexpected event like disability; situating (placing) the educational intervention in a time frame that respects the needs of all siblings; maintaining and/or re-establishing the family boundaries (siblings are not parents); maintaining a shared family project.

If all family resources – both human and economic – are devoted solely to responding to the needs and demands of the disabled child, there is no space for personal expression and growth for the other children, who find themselves "crushed" by the sometimes cumbersome presence of the disabled sibling.

Notes

This contribution, developed and shared jointly by the two authors, was drawn up as follows: paragraphs 1 and 5 by Roberta Caldin and paragraphs 2, 3 and 4 by Alessia Cinotti.

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