Different mirrors
Sibship, disability and life phases
Specchi diversi
Fratria, disabilità e fasi della vita

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Although siblings perceive the differences between themselves and the disabled brother/sister - through observation, everyday interaction and direct comparison – without any gradual and specific guidance, they have great difficulty in understanding the actual situation and in finding answers for the various questions concerning their disabled brother/sister that may spring to their minds. As a result, without appropriate and careful explanations from adults, siblings risk building a distorted and even dysfunctional image of their brother/sister's disability, particularly in early childhood but also – albeit to varying degrees – in adolescence and adulthood.

Based on these initial assumptions, 2009 witnessed the start of the research project *"Essere fratelli. Vivere la disabilità" ("Being siblings. Living with disability"),* the aim of which was to investigate – from an educational and pedagogical perspective – *sibling relationships and disability*.

How to *support* and *provide guidance for* the life plan of brothers and sisters of the disabled? Which *actions* and *educational interventions* would help to guarantee this?
Starting from (and through) the initial question of *"how to communicate the diagnosis to siblings of disabled people",* the research highlighted some interesting *educational dimensions* that led us to refine our thoughts, in terms of the importance of supporting the siblings of the disabled person as well as the parents. The following considerations focus on the main conceptual issues linked to the communication of the diagnosis, sibling relationships, relationships with parents *in the different life cycle phases*: childhood, adolescence, adulthood.

Keywords: sibship, disability, life phases, life plan

abstract

III. Esiti di ricerca   95

*   This contribution, fully shared by the two authors, was drawn up as follows: paragraphs 1, 2, 6 by Roberta Caldin and paragraphs 3, 4, 5, 7 by Alessia Cinotti.

I am one of five brothers and sisters. We live in different places, some of us live abroad; and we don't write to each other often. When we meet, at times we are indifferent to each other, or distracted. But among us, it takes just a word. A word, a phrase [...] and we fall instantly back into our old relationships, our childhood and youth, bound intrinsically to those phrases, those words. One of those phrases or words would enable us siblings to recognise each other among millions of others in the darkness of a cave (Ginzburg, 1963).

1. Introduction

While studies into families with disabled children began in the Seventies, researchers' interest in the *sibling relationship* with a disabled brother or sister is even more recent.

For many years, research into sibling relations focused on the *effects* generated by the presence of a disabled brother/sister: each time, researchers concentrated on the analysis of precise *structural variables*, such as "gender", "birth order" or "family structure", in an attempt to identify which factors most influence the process of adapting to disability. In the early Nineties, studies aiming to identify the factors that would aid understanding of how sibling dynamics work were published both in Italy and internationally (Furman, 1993; Stoneman, Brody, 1993). These researchers focused their attention on the *relational characteristics of the family* (emotional climate, marital harmony, conflictuality, etc.); the *characteristics of the parental couple* (educational style, time effectively dedicated to parenting, coherent educational strategies, etc.) and the individual parents (age, social and cultural status, ability to cope, etc.); as well as on the *characteristics of all the siblings* (disabled and otherwise) including gender, age, nature, type and level of disability.

The research projects progressively shifted their focus from the *effects* – that a brother/sister brings to the sibship – to the processes characterising the sibling relationship, investigating its wealth and plurality of forms, in an increasingly systemic manner, aiming to create a corpus of knowledge covering the whole life span, integrating different research methodologies.

The most recent studies (Iraite, Ibrarrolla-Garcia, 2010; Dykens, 2006; Voizot, 2003) show that to support and guide the brothers and sisters of disabled siblings in their life paths a *balanced, well-pondered approach* is required, that is not merely limited to emphasising the emotions and negative effects of the disability, as many research works have done, nor to underlining the positive effects and benefits that the experience of disability brings, as another research area has attempted to describe (Conners, Stalker, 2003).

A fundamental role, for the purposes of the acknowledgement[1] the disability

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1   "Acceptance is not however a simple act of will but in fact rather a complex process. Acceptance is not an act of heroism, a huge sacrifice that goes against one's own feelings, nor does it require

of the disability (Montuschi, 1997), is played by the *parents* within the family environment: the family is the context *par excellence* where we learn to understand and get to know the disabled brother/sister.

The *parent-child relationship* is multifaceted, fraught with difficulties and perplexities. Some parents deliberately try to hide the truth about the child's disability from the other siblings, vainly hoping to protect them for as long as possible, while others are unable to tell their children because they do not know where to begin or what to say, despite their desire not to conceal the truth. Still others think that there is no need to explain to their children as they are still too young, or because they believe that as they grow they will become aware of their sibling's disability on their own. Equally there are parents who provide unclear information to their children, in a negative, hurried or indirect manner, and this can create an obstacle to their understanding of the new situation.

Although siblings perceive the differences between themselves and the disabled brother/sister – through observation, everyday interaction and direct comparison – without requiring any gradual and specific *guidance*, they have, nonetheless, great difficulty in understanding the situation and in finding answers for the various questions concerning their disabled brother/sister that may spring to their minds. *Acknowledgement* of the disability is even more difficult in cases where there are no particular characteristics that underline the disability of the brother/sister (hearing aids, technological equipment required for survival, clear physiognomic traits, etc.); or if there is only a minimal age difference between the siblings, or if the disabled brother/sister is the oldest.

So if the siblings are not provided with appropriate and careful explanations by the adults, they risk building a distorted and even dysfunctional image of their brother/sister's disability, particularly in early childhood but also – albeit to varying degrees – in adolescence and adulthood.

However, despite the immense wealth and value of these important areas of study, many questions remain open and unanswered. Therefore, understanding how and why some children with a disabled brother or sister have an absolutely regular development while others have difficulties still remains a mystery.

We must remember that in the current Italian context there is no reference protocol for communication of diagnoses to siblings, or for effective *educational-pedagogical interventions* for tackling the *crucial knots in sibling relationships*, starting from diagnosis communication, understood as a continuous and repeated life-long process (Caldin, 2011).

2. Research methodology

Based on these initial assumptions, 2009 witnessed the start of the research project "*Essere fratelli. Vivere la disabilità*" ("*Being siblings. Living with disabili-*

any deceptive modification of one's own negative opinions to render acceptable a reality that reason refuses. It is therefore neither resignation nor deceit: it is a simple statement of reality, the acknowledgement of events as well as the emotions that these events arouse in us" (Montuschi, 1997, p. 83).

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ty")[2], the aim of which was to investigate, from an educational and pedagogical perspective, one of the least studied topics in the field of disability: *sibling relationships and disability*. This research links to the theoretical and conceptual frameworks of inclusive education (Ainscow, Booth, Dyson, 2006; Armstrong, 2003; Ainscow, Booth 1998; Stainback and Stainback, 1990), an approach which demands that we work firstly on the contexts and then on the individual, transforming the specialist response into an ordinary one, referring to a social model of disability and to the process of empowerment that places the disabled person and his/her family at the centre of all decision-making processes (D'Alessio, 2011).

Starting from (and through) the initial question of *"how to communicate the diagnosis to siblings of disabled people",* the research highlighted some interesting *educational dimensions* that led us to refine our thoughts, in terms of the importance of supporting the siblings of the disabled person as well as the parents right from the moment of diagnosis communication.

This is an exploratory research project. Its initial hypothesis focuses on the importance of ensuring educational actions for the siblings of the disabled person. Here we hypothesise that by working as early as possible with brothers/sisters we should be able to help the non-disabled sibling to relate to this new reality with less difficulty, fear and lack of understanding, with positive knock-on effects both in the sibling relationship and in the construction of the identity of the non-disabled brother/sister.

The main objective of this research was to obtain more information on this subject, focusing on educational and pedagogical dimensions, starting with the needs and difficulties that siblings may encounter in their life plans (who are the siblings of disabled people?, what are their difficulties and their resources? how do they live with the disability? etc.).

The research, carried out in Italy, included a preliminary exploratory phase of the topic, followed by a second phase dedicated to studying the emerging results, through the administration of a semi-structured questionnaire to a larger group of people with disabled siblings using a quantitative method.

The first research phase focused on a small reference group of 4 brothers and 8 sisters aged between 16 and 45. With a descriptive and qualitative function, in this phase in-depth interviews were administered and the data obtained was then analysed and coded. The choice of in-depth interviews was based to a great extent on the objectives of this first research phase. We aimed to investigate the personal standpoints, experiences of the disability, memories linked to the birth

Further information: Montuschi F. (1997). *Fare ed essere. Il prezzo della gratuità nell'educazione*. Assisi: Cittadella. Montuschi F. (1993). *Competenza affettiva e apprendimento. Dalla alfabetizzazione affettiva all'apprendimento.* Brescia: La Scuola.

2   The research was carried out by Roberta Caldin (Scientific Director) and Alessia Cinotti. Further information: Caldin R., Cinotti A. (2012). La comunicazione della diagnosi. Un'esperienza con i fratelli e le sorelle di persone disabili. In M. Carrozzino, P. Ruffinatto (Eds.). *I paradossi della disabilità. Autonomia Capacità Dipendenza*, Roma: Nuove Frontiere; Caldin R., Cinotti A. (2011). Être frères. Vivre le handicap. In E. Catarsi (Ed.). *Educazione familiare e servizi per l'infanzia/ Education familiale et services pour l'enfance* (pp. 165-169). Firenze: University Press.

of a disabled brother/sister, as well as the difficulties and perceptions. Moreover, as sibship is an unexplored area, our aim – in this phase of the research – was to define a more specific field of investigation (to which the second phase was dedicated) compared to the initial area of enquiry.

In this first phase, the interview included simple questions formulated directly, "Can you tell us …?", "Do you remember …?" to allow the brother/sister to openly discuss the question in hand. This method allowed the interviewees to talk freely and choose where to start from and what to tell: we noted that some interviewees offered very significant personal anecdotes, digressed into other important reflections and in some cases provided long introductions to their answers. This information was very helpful as it allowed dimensions to emerge that would have been difficult to hypothesise from the outset, based solely on the reading of the bibliographic references on the subject.

In the second phase following this initial research, we investigated how to *support* and *provide guidance for* the life plan of brothers and sisters of the disabled and which *actions* and *educational interventions* would help to guarantee this. This research phase was based on the administration of a semi-structured questionnaire to a sizeable group of people with disabled siblings (Tab. 1).

The group of 76 non-disabled siblings includes 61 females (80%) and 15 males (20%), aged between 16 and 68. The sibling age group is very wide, as our aim was to investigate the issue of sibship in the *different life cycles,* to explore the *transformations* and *features* of sibling relationships. Due to the complexity and delicacy of the topic, we decided not to directly involve children with disabled siblings, preferring a target composed of adolescents (6%), young adults (41%), and adults (53%). Moreover, to understand the heterogeneity of sibling relations, we chose to include in the research both younger (32%) and older siblings (68%) of the disabled person, from the whole of Italy, trying to involve as many regions as possible, from the South and the Islands (11%) to the Centre (34%) and the North of Italy (55%).

| GENDER	BIRTH ORDER[3]	AGE GROUP	PROVENANCE
Female (61) 80%	Minors (25) 32%	Adolescents (5) 6%	South and Islands (8) 11%
Males (15) 20%	Adults (52) 68%	Young adults (31) 41%	Centre (26) 34%
Total (76)	Twins 0%	Adult (40) 53%	North (42) 55%

Tab. 1: Group of non-disabled siblings

In this second phase, the questionnaire administered to the brothers/sisters included a section on their disabled siblings (age, type of disability, etc.) to understand the features of the sibling relationships, considering the whole sibship and not merely the non-disabled brother/sister. The personal data indicated a total of 72 disabled siblings there are 72 disabled siblings (42 females and 30

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3   The sum is greater than the total (76) as one person has two disabled sisters and according to birth order covers the role of both older and younger sister.

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males), aged between 6 and 60. 13% have mild disabilities, 52% average disabilities and 35% complex disabilities.

Moreover, for the purposes of our investigation of sibling relationships, it is important to point out that 81% of the disabled siblings live with their relatives, more specifically: 64% live with the parents, 14% live with the sibling's family, and 3% live only with a brother/sister. 6% on the other hand live outside the family: 3% live in a residential centre full-time and the other 3% from Monday to Friday only (Graph. 1).
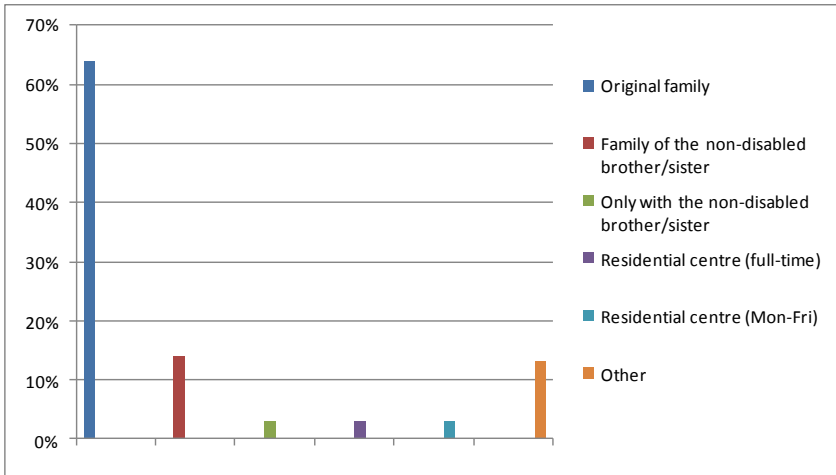
Graph. 1: The group of disabled siblings

In the research, in both phases, central importance was given to the brothers and sisters of disabled persons, disseminating their testimonials and points of view to prepare a path for the *transmission* of *knowledge* and *competences* drawn from personal experience and everyday life. Like the parents, siblings are *experts*: they bear witness to precious knowledge that needs to be acknowledged, promoted and integrated with that of professionals (teachers, social and educational workers, health professionals, etc.), within an effective and profitable partnership.

Analysing the emerging data, we obtain a rich framework of suggestions and cues for thought; as it is impossible to study them all, the following considerations focus on the main conceptual issues linked to the communication of the diagnosis, sibling relationships, relationships with parents *in the different life cycle phases*: childhood (paragraph 3), adolescence (paragraph 4) and adulthood (paragraph 5).

3. Sibling relationship during childhood

Studies into developmental age, above all in the field of psychology, teach us that generally until the age of eighteen months the arrival of a new sibling creates very few problems; on the other hand, between eighteen months and three

years the impact may be tougher and create greater difficulties in adapting. At around four to five years, children are assumed to have the maturity required to handle the frustration with a greater ability to adapt (Capodieci, 2003, p. 123). Usually the child or children welcome the new baby with a mixture of affection and excitement, not fully aware of the changes that the event will bring to their lives. In actual fact, for many children the birth of the brother/sister represents the first real experience of separation from the mother, who is admitted to hospital for the birth of the new baby.

For many scholars, the birth of a sibling is a stressful experience, particularly for the first born; other researchers, on the other hand, consider the birth of a sibling to be a non-stressful event, the associated changes of which can be faced naturally by the majority of children (Dunn, 1998; Dunn, Plomin, 1997; Cicirelli, 1995). For example, after the birth of the brother/sister, some children present regressive behaviour: they may become more demanding, have episodes of bed-wetting, lose sphincter control or have difficulty sleeping. Other children, on the other hand, show greater maturity than could be expected, and for them the fact of being the older sibling becomes a matter of pride.

It is important to note that, for some aspects, the birth of a disabled sibling is not so different from the birth of a non-disabled brother or sister: the first born and other children have reactions (regressions, excitement, etc.) and feelings (happiness, jealousy, curiosity, etc.) that any child may have following the arrival of a new member of the family(Giallo, Gavidia-Payne, 2006).

However, the birth of a disabled child should be considered a critical event for the whole family, including the brothers and sisters, who – irrespective of their age – feel and perceive the tension, sadness and worry of the parents.

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> When I entered the room at the hospital, I immediately realised that something was wrong, because the crib next to Mum was empty, my brother wasn't there. (E.L.)[4]

> There are 16 months difference between me and F, my Mum always tells me that I understood straight away that something had changed, even though I continued to act as normal, without asking questions. When I was around two and a half, we went to visit A, another Down's Syndrome child, and when we left the house I asked: "Why do F and A have the same eyes?" My Mum didn't tell me but I think that my curiosity was a great relief for her, and the starting point for her to tell me, in her way, that F. had Down's Syndrome. (F. V.)

Moreover, in contrast to adults, children may have little knowledge of the disability and the nature of some conditions can be very difficult to understand; Glasberg (2000) indicates how the difficulties in comprehension can be widely attributed to the abstract nature of the concepts linked to the disability itself (Gardou, 2012).

The abstractness, as an element that interferes with the understanding of the disability, is also widely confirmed in our research, where more than half of

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4   All the testimonials are taken from the research work "*Essere fratelli. Vivere la disabilità".*

those interviewed (72%) stated, in response to the question *"Before the birth of my brother/sister I had never seen a disabled person",* that they had never seen a disabled person or did not remember, demonstrating how disability is not always a common and/or familiar experience for the majority of people.

> *For example when my sister was born I had never heard the word Down, nor did I have any experience with friends and/or acquaintances. The transition for understanding that it was not a disease but rather a permanent genetic condition was very complex. (L.B.)*

> *I was 9 years old and knew nothing about Down's Syndrome, I thought it was a serious disease. (M.L.)*

From literature it emerges that in childhood one of the aspects that can create the greatest distress is precisely the lack of early and spontaneous explanations by the parents. The role of the parents towards the other children is very important, following the birth of a disabled sibling: *spreading hope* and *distributing suffering* (Meltzer, Harris, 1986) are two of the main *functions* the parents should actively implement in order to accommodate, reassure and at the same time limit the emotional experiences of their children. However, parents are not always able to understand that, as children, the brothers and sisters have too limited a life experience to be able to take care of the disabled sibling and/or place the problem of disability in their own existential perspective (Capodieci, 2003).

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> *Mum, T. [the disabled brother]and I, all together in the big bed, and Mum explained lots of things to me: "You see, children with Down's Syndrome have eyes this shape, slightly elongated." These are nice memories. (M.M.)*

> *Even small things became a tragedy, for example my sister ate very little and this was a tragedy, then she began to eat yoghurt, but only one flavour... and that was practically a tragedy too. (I.R.)*

> *We all worked very hard, I used to go to the check-ups with my parents and I listened. At home we did physiotherapy, as if it were an organised game. (I.R.)*

McHale and Harris (1992) state that the sibling's acknowledgement of their brother/sister's disability takes place very early, around three years; Capodieci (2003), on the other hand, demonstrates that strong awareness of the disabled brother/sister's disability is acquired only later on, during the primary school years (six to ten years), through a comparison of their own siblings with friends and schoolmates. The study by Glasberg (2000), moreover, underlines how the progressive cognitive development of the growing sibling does not always correspond to an equal increase in the comprehension of the brother/sister's disability.

It is noted how the brother/sister – despite their strong cognitive skills and capacity for abstract, processed thought, in terms of the understanding of the disability – show difficulty in overcoming a preoperational stage of thought, a form of magical thought (such as the fear of contagion) which affects the process

of acknowledgement of the disability. This discrepancy between the level of acquired maturity and the processing of the disability, which may also be due to emotional interference (e.g. fear, etc.), is very frequent not only among children but also among adolescents.

> With C. I think I understood very well for two reasons: a friend of the family had Down's Syndrome, and also because we attended the parish and sometimes I came into contact with other children with problems.(L.E.)

> When I was eight, my mother told me that my brother had problems, and I was afraid of the word Down. I loved my brother, who at the time was two, he had just learned to walk... that strange word couldn't change everything. I was frightened. (F.C.)

> The awareness of his deficit grew slowly, when I was able to understand, my parents carefully explained his encephalopathy to me, the days he spent in a coma and everything that came afterwards. (F. L.)

Finally, many studies show how the process of *role crossover* – the exchange of roles that occurs between siblings when the non-disabled younger sibling reaches and overtakes the skills of the older disabled brother or sister (Farber, 1993) – is a key moment for the acknowledgement of the brother/sister's disability: this takes place both when the disabled brother/sister is older and when there is a limited age difference between the siblings. At one point it will be very clear how the development of one brother/sister proceeds regularly, while the development of the other remains stable, with clearly different abilities.

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> I was much younger but for example I was much faster than she was, or in other things I was much better than her. (P.Q.)

> I saw her as my equal, when we were small we always played together... then she began to close herself off, become isolated, not speak, and then I understood. (L.E.)

The research demonstrates that for some years the brothers/sisters do not fully understand the disability of their sibling, and tend therefore, as children, to become hostile and jealous towards the fact that their parents dedicate so much time and effort to their disabled brother/sister (Dew *et al.,* 2008).Without appropriate information and explanations, children develop the idea that the parents love the other child more, creating a sentiment of exclusion.

> I remember they used to say that he was unlucky, a poor child. I didn't understand why they said this, I thought that I was the unlucky one; he was the one that got all the cuddles and attention. (L.E.)

> Mum and Dad did everything for him, some I knew well enough, he could do for himself, but no.... all the focus on him. (E.L.)

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4. Sibling relations in adolescence

As mentioned in the previous paragraph, the slow and gradual process towards understanding the disability continues also into adolescence. In particular, in this phase of the life cycle, the sibling's disability implies a whole series of considerations also concerning the social context: shame, embarrassment, discomfort towards friends and acquaintances due to the health conditions of the disabled brother/sister and his/her behaviour are very frequent *emotional experiences* (McMillan, 2005).

In our research, the siblings responded as follows to the question *"In your opinion, siblings should be helped/supported..."* (Graph. 2):

- in processing their personal emotional experiences (anger, guilt, embarrassment, solitude) 77%;
- in their relations with their disabled brother/sister 44%;
- in social relations (schoolmates, friends, partners, etc.) 44%;
- in understanding the disability (causes, limits, potential) 33%;
- in their feelings towards their disabled brother/sister 22%.
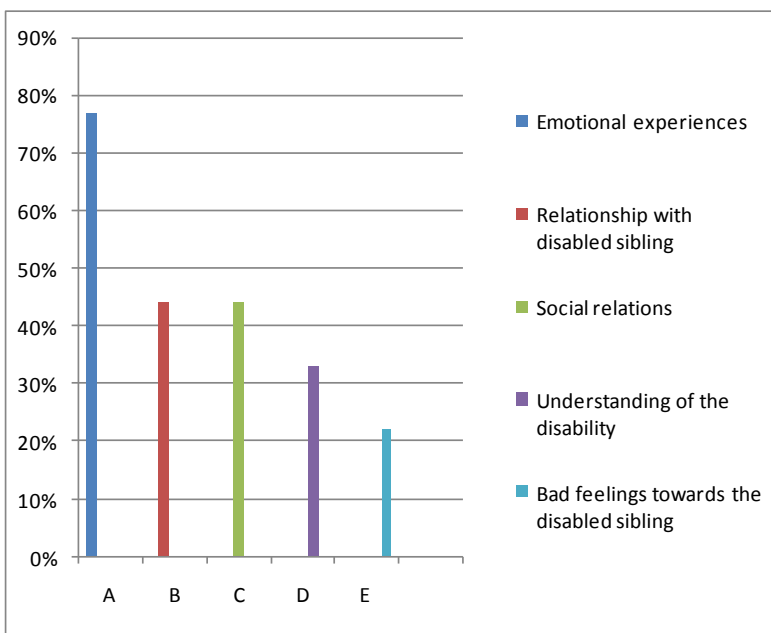
Graph. 2: Areas to be supported according to the needs of the siblings

It appears that one of the priority *needs* of the siblings is to have *support* and *guidance* in the processing of *emotional experiences*; the feeling of isolation and not having anyone with whom to share the experience of having a disabled brother/sister represents a gap to be filled through *educational* actions of a *preventive* nature, aiming to support this area of the personal sphere.

Great importance is also given to the sibling relationship itself, and how – according to the siblings – this needs to be sustained and cultivated, also through the *mediation* of adults (Germain, 2008). Sibling relationships, above all in cases of disability, cannot be left to their own devices: parents can play an important role in helping the siblings to get to know each other, to find their own balance, and (re)define borders and proximities, respecting the needs of all the children (Saint-Martin, 2012).

Another area that siblings require support with lies in *social relations* (Lefebvre, Sarfaty, 2008), with friends, schoolmates but also other acquaintances (including the stares of strangers).

In this regard, it is of fundamental importance to point out that the need for support within the social sphere does not consequently mean that the siblings of disabled persons have irregular development and a high risk of difficulty in individual and social adaptation, but rather that the social sphere also needs to be recognised and supported, with a global vision of the person. Therefore, we agree with other scholars who claim that many siblings of disabled people grow up to have fulfilling and totally satisfactory lives (Ianes, 1993).

In adolescence, the process of differentiation with the brother/sister (and the family) becomes progressively clearer as years go by: brothers and sisters tend to be less involved in the care of the disabled sibling, partly due to the natural process of separation from the parents, and partly because they are attracted to their peer groups, which in this stage of the individual life cycle play a key role in developing identity. This is why the dimension of *social relations* could become a priority area for educational interventions targeting the siblings of disabled persons: it is fundamental to help these brothers and sisters to find the right balance between their own exclusive time, a time and space for them to dedicate to themselves and their own free time, time for their friends, and time to dedicate to their disabled sibling, in order to avoid the so-called *social closure*[5] which often characterises families with a disabled child.

During adolescence, often brothers and sisters note the re-emergence of negative feelings and perceptions of childhood – such as *guilt* and *shame* – also due to the smaller amount of time they spend in the family or to a whole series of opportunities, in terms of both relations and abilities, that the disabled sibling has only partially.

> *One thing I don't like so much is that now I can do things that he can't like having a moped or getting a driving licence. He has been explained all these things, but to "relieve" his pain, whenever I can I take him out for a drive or a ride on the bike, sometimes he asks me first and even if I don't feel like it I make an effort and off we go. (M.M.)*

On the one hand, non-disabled siblings long for new experiences, separating themselves from their adult reference figures to become more autonomous (Korff-Sausse, 2003); on the other hand, they feel the resistance and tension in the

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5   *Social closing* refers to the closure of the family group towards the outside world, dictated by feelings of distress, shame, difficulty, etc.

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family generated by these changes, and may be affected negatively by the idea that without them the disabled brother/sister is alone.

Other adolescents are burdened with too much responsibility by their parents, and their sense of duty compels them to spend much of their free time with their disabled brother/sister, without being able to cultivate their own interests, depriving themselves of those encounters and experiences that are indispensable for personal growth.

> *My parents are sad that G. has no normal friends, but I am less harsh than they are: then again, I have no disabled friends, and don't think it's fair that G. always has to come out with me and my friends. (M.B.)*

> *For me adolescence was a terrible time, my parents had mortgaged our lives for us, they used to say, "It will be up to you to look after your sister." (E.B.)*

> *I remember that I spent part of every afternoon helping my sister with her homework. (E.B.)*

For these reasons, during adolescence it could be useful to *provide guidance* to both brothers/sisters and parents – in different ways and with social and educational supports – in order to help them understand that in adolescence it is totally physiological for siblings to move away from the family nucleus, distancing themselves from their disabled brother/sister, and coming into conflict with the parental role. This emotional and physical detachment is necessary in order to review and transform the existing ties and balances, so that the sibling relationship can develop.

> *My parents assigned me a parental role, for a time my sister called me "Mum". Until I felt that this was too great a burden for me. Then I took the decision to leave home, I had to get away from that situation, also physically. When I was 20 I went to live with some friends... My parents didn't understand and thought that I had abandoned them, considering me a traitor. (L.B.)*

> *I was always out and about with my friends. (F.E.)*

Some adolescents reach a greater level of maturity than their peers, precisely due to their particular family situation; this is also confirmed in our research, where 59% of people responded that they *"strongly agree"* with the statement that *"I developed greater sensitivity than my schoolmates"*. Within the peer group, above all when friends take little notice or are misinformed about the disability, some adolescents fear they will be labelled as the "brother/sister of the disabled person", and to some extent fear being rejected, considered different and mocked.

Usually, on the other hand, peers with non-disabled brothers and sisters start to develop a far more symmetrical relationship with their own siblings, experimenting a more equal relationship within the family, which is an important testing ground for entering into the world beyond the family.

During this phase, some adolescents develop a more authoritarian relationship with their disabled brother/sister, in which they play a dominant role, more asymmetrical and distant. Parallel to this, this relationship method, in which a "dominant" role is played, may also run beyond the family boundaries into other interpersonal relations, leading to some difficulties in building harmonious relationships, and balance needs to be found in the delicate process of give-and-take that friend relationships require.

In this transitional phase, from childhood to adulthood, siblings begin to query their own future, questions that also partially affect the disabled brother/sister: they wonder what their partner may think of them having a disabled sibling, and his/her need for care and assistance; they wonder what will happen one day if they have children; they wonder what will happen when their parents become too old to act as caregivers. As explained by Binda (2004) these are very complex issues, and even the maturest adolescents have trouble in finding a sufficiently reassuring answer to these concerns.

5. Sibling relations in adulthood[6]

In contrast to the two previous ages, sibling relations in adulthood is the life cycle least explored in the pedagogical field. The consideration for this time frame is widely due to the new life prospects of disabled persons. In fact, a significant increase in the average age of disabled persons has been recorded, and in contrast to the past it is frequent for people with disabled siblings to experience this relationship also in adulthood (McMillan, 2005). Moreover, this longer life span has led to situations in which the disabled person may lose his/her parents, yet still need significant care and daily assistance. Thus, it is important to understand how to continue the sibling relations, after the years of adolescence, as many younger and older brothers and sisters will very probably have to replace the parents and take over the care of their disabled sibling first hand.

During maturity, when the relationships between siblings tend to become symmetrical and on equal footing, in the case of disability sibling relations are much less balanced and become far similar to the parental model of relationships. In our research, 61% of people stated that they agreed or strongly agreed with the statement that *"the relationship is asymmetrical, even though we are both adults".* The asymmetry of roles is even more obvious in the cases in which the brother/sister has a complex disability, resulting in the serious compromising of functions and personal autonomy, with clear difficulties on a cognitive, linguistic and socio-relational level.

> *We get on well together, we make sure we spend time together just the two of us, I leave my children at home and we go to do the shopping. (L.B.)*

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6   In the research "Essere fratelli. Vivere la disabilità", the focus on sibling relations in adulthood is still underway. In this article we can therefore only present the first (and partial) results of this phase of the survey.

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> *With M. I couldn't say, her disability is very serious, she has no autonomy, the only other person she has relations with is my mother. She does only two things: she licks the kitchen sponge if she's thirsty and she moves the knob on the oven to make pizza. There are many negative aspects, you have to dedicate yourself to her 100%, she is an exponentially demanding sister. I can't do anything with her, I can't even go to the supermarket. She will scream for no reason, people stop and stare... I can't cope. (F.E.).*

Generally, however, relationships in adulthood tend to be marked by less conflictuality than in childhood and adolescence and more satisfaction, also due to a much more significant understanding of reality compared to the past. In adulthood, it is seen how brother/sisters about to have children return to their memories of the birth of their disabled sibling, and in some cases wonder whether their child will have problems. Unconsciously, often the fear of having a disabled child remains, both in brothers and sisters, an echo that rekindles the childhood fear of "getting sick" and becoming like the disabled sibling.

> *Much later, when I wanted a child of my own, my parents told me that I shouldn't worry because they had had all the tests available done and there were no genetic issues. When I was pregnant with my first child they gave me all the photocopies of the tests; I decided to do a chromosome map, while I was pregnant. I remember that my brother did it too, and also did the test for fragile X syndrome. I would have liked a third child, but thought that perhaps I had been lucky to have two healthy children and it wasn't worth tempting fate. I could not have coped with a child with problems. (F.T.)*

> *I am haunted by the memory of my mother telling me how things had gone [referring to the sister's disability], including her pregnancy with me and near the birth. (F.L.)*

> *My partner is expecting twins and I wonder if our children will be born with problems. We both decided to have all the possible tests done during my partner's pregnancy. (F.E.)*

In our research, to the question *"As I child I was afraid of catching my sibling's disability"*, 67% stated that they *"did not agree"* with this fear, as if it was never felt by the majority of them; while a much lower percentage (6%) responded positively to this question.

We think that as time passes these adults have learned to give a different name to these fears and memories of the past, and that the focus of the brother/sister moves – in adulthood – in other directions, towards new urgencies to be dealt with:

– the parents becoming elderly, or the death of one of them;
– the practical and possibly legal responsibility for the disabled sibling;
– worries about the disabled sibling's future;
– uncertainty over the willingness of one's own partner to take this situation on board;
– worry over how to reconcile the needs of one's own new family (e.g. children) with the needs of the disabled brother/sister.

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The question of "who", after the parents, will look after the disabled brother/sister, and how, remains a central issue in the family system.

As explained by Binda (2004), positively and negatively, the care dimension represents a constant in the sibling relations in families with a disabled child, and in particular during maturity. And it is around the *process of taking responsibility* for the disabled brother/sisters that we need to structure a *global life plan* that considers the needs of all siblings – disabled and otherwise – guaranteeing each of them the right to a good quality of life, respecting all parties.

In our research, to the question *"in future, my sibling will come and live with me",* 35% stated that they *"agreed"* and 16% that they "*strongly agreed*" with the statement: from this data it can be deduced that many brother/sisters will take care of their disabled sibling after the death of their parents. All this could be possible thanks to the *adoption of a parental role* and the *support* and *willingness of partners* and children.

Moreover, the choice of the brother/sister to take care of the disabled person does not appear to be significantly influenced by gender, in contrast to what happened during childhood and/or adolescence where the fact of being brother or sister would affect the involvement in care and the role play within the sibship.

In adulthood, in fact, the *support* is more influenced by elements that are extrinsic to the relationship (e.g. willingness of the partner, economic resources, geographical position, etc.) and intrinsic elements, such as the quality of the sibling relations, the frequency of past contacts, level of affection and emotional involvement.

> *After the death of my parents, I would never want to put my sister in a residential home, as she cannot communicate and if they treat her badly I would never know. I am rather wary, and prefer to keep her with me. (M. A.)*

> *Currently I live a long way from my brother, he still lives with our father in Southern Italy. Although, looking to the future, because now my father is elderly, I am starting to make contact with the local services, to find out what possibilities I have here in Bologna. I live here with my wife and children, my brother will come here, we will not move south. (M.A.)*

> *My brother came to live with me [I was married at the time] but after a while my wife did not accept the situation, and she left me. Now there is only me and my brother, and I must say we get on just fine. (M.A.)*

A *global life plan* includes various forms of *care*: we think it is fundamental to state that also the choice of a residential centre is synonymous with having made a choice based on *the care* and well-being of all members of the family, many of these, for example, members of a new family (Genevois, 2012). A project focusing exclusively on the most fragile member is a project destined to fail over time, creating difficult and unsatisfactory situations for everyone involved.

> *I chose to put my sister in a residential centre, we see each other often, spend time with my children, but she lives in the centre. I don't think I love her less for having decided not to keep her at home with me. (F.A.)*

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6. Conclusion and pedagogical perspectives

When a disabled child is born, right from the outset the family needs to be attended to and provided with guidance in these new, almost always unexpected and unwanted circumstances. It is undeniable, as Sorrentino explains (2006) that the impact with the disability is a very severe test bench for the whole family: it undermines the generative skills of the parents, in terms of their ability to care for the children, with effects and consequences for the children themselves.

The family thus appears vulnerable, fragile and must not be left alone: in this scenario, it is indispensable to design guidance plans that combine educational and social support with psychological support for the family group, including brothers and sisters.

The acknowledgement of the child/sibling's health conditions does not come automatically when the news is broken, but the first interview can trigger a process of *recognition* which, first and foremost, requires time and needs *inculturation* and, for this reason, needs to be reformulated, reorganised and completed (Canevaro, 2008).

In general terms, the approach involves a specific *right to information* for the brothers and sisters, which starts with the notification of the diagnosis and continues throughout life (childhood, adolescence and adulthood), through a recursive method that is gradual over time (Caldin, Cinotti, 2011; Scelles, 2008).

The notification of the diagnosis coincides with the start of the *support* to the family by the social services (and the local community, where possible); it is hoped that the siblings be given the chance to talk, with different methods and in different situations, both with the *parents* and with a competent, trained and empathic *professional figure*. In fact, when a family has a disabled child, parents often feel that they invest a huge amount of energy on him/her, in an attempt to deny the deficit or as compensation for the aggressive/expulsive feeling they have towards him/her.

This profusion of care for the child is inevitably to the detriment of the other children, who may begin to experience feelings of anger, jealousy, expulsion from the family nucleus, guilt for wishing that the sibling would die.

In these cases, it could be very effective for the brothers and sisters to be able to talk to a professional figure, outside of the family both physically and emotionally, who can help them to become aware of their own experiences.

The recognition and welcoming acceptance of these contrasting feelings may help the sibling to cope with the competitiveness and hostility towards the disabled brother/sister in a way that may help the relationship to evolve in a more serene manner with less fear and anxiety.

Parents and children live together on a day to day basis, and particularly during childhood the mother and father are important references for the child (McMillan, 2005); for this reason it is fundamental for adults, within the intimacy of their own family, to *be available and responsive* to their children, creating a climate that is open to *dialogue and accepting,* as they occur, all the child's experiences from crying to curiosity and questions to anger and silence.

Every question posed by the child – at any age – deserves an answer: parents cannot shirk this responsibility, but rather depending on the age of the child and his/her cognitive development, must provide the most appropriate information

for the given time. Also in this case, we believe it is important to be authentic and honest with one's own children: it is preferable to reply with a sincere "I don't know" than give false illusions or reassurances.

It is not always necessary to go into detail when explaining things; above all early on, children can simply be told that there are problems affecting the sibling's health and sincerely say that it is very complex to explain it, but as soon as the situation is clearer they will all talk about it together. The important thing is not to pull the wool over the children's eyes, pretending that nothing is wrong when it clearly is. Information changes the perspectives of fear, in many cases basic knowledge of the disability can reduce the related distress, anxiety and uncertainty. We therefore need to offer explanations on the sibling's condition constantly, in order to avoid the children making incorrect suppositions, at any age.

The topic tackled is particularly complex and we therefore think that it is, on one hand, very difficult to draw conclusions or offer guidelines that are valid for all life stories, but on the other, we think it is necessary to outline the general *pedagogical and educational indications* concerning the initial question of how to *"support and guide the brothers and sisters of disabled persons".* From the life stories, some *experiences emerge* – the difficulty in telling friends that they have a disabled sibling, being mocked, jealousy towards the sibling, a feeling of being neglected, excessive responsibility etc. – *and difficulties that are common* to many brother/sisters (relationship with the outside world, difficulties in understanding the disability, questions concerning the responsibility for the disabled sibling after the death of the parents, etc.).

One *good practice* could be to offer *support* (Giallo, Gavidia-Payne, 2006) right from the very beginning, and continue to support and offer guidance to the whole family during the life path, establishing a global life plan.

Brothers and sisters must be involved and made an active part of the family situation, and in the matters concerning the disabled sibling they can offer great emotional support, but at the same time they must be given their own time and space for autonomy and independence.
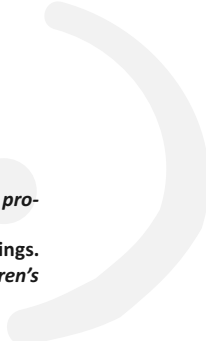
Family well-being is achieved also through the personal realisation of each member of the family. Inclusion needs significant adults (Sapucci, 2007). From this standpoint, inclusion is seen as a broad "ecosystem" able to foster the co-evolution of each and every one (Canevaro, d'Alonzo, Ianes, Caldin, 2011).

Finally, we think it is equally important that, despite the fatigue, sorrows and lack of time, the family manage to maintain and/or redefine a *space* dedicated solely to *pleasure,* having fun, sharing and light-heartedness: within the family, the children must also have positive and emotionally satisfying experiences with their parents, linked to the "pleasure of spending time together".

Through this research, we processed and interpreted the "knowledge" *transmitted* and offered by the brothers and sisters interviewed, and the co-constructed results emerging have served to renew the knowledge itself, characterising it with social and cognitive elements that were lacking at the outset. A project-based, decentralised knowledge that considers *transmission* as a co-constructive and renewing opportunity in which the space of the relationship (between parents and children, between siblings, between educators and parents, etc.) is the place that promotes change and participation.

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