# Families and disability: Being resilient together. An exploratory research on the reciprocal representations of families and educators<sup>1</sup>

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This article presents a qualitative research intended to explore the characteristics of the relationship between educators of educational/rehabilitation services, children with disability and their family members. Specifically, we considered: (a) the educators' *implicit theories*, or representations, of families with a child with disability and their effect on the educators' professional practices, (b) the family representations of the educational/rehabilitation services and (c) the processes of resilience activated to cope with the disability. Twenty-two educators participated in three focus groups, and three families with a child with disability (age range: 9-15) were interviewed and video-recorded in their homes. Results show a partial overlap between educators' and families' representations. Implications for the development of a participatory and co-evolutionary approach that strengthen the *resilience* of families and their children with disability are discussed.

Keywords: family relations, disability, implicit theories, resilience, qualitative research.

We contend that disability definitions are not rationally determined but socially constructed.

Despite the objective reality, what becomes a disability is determined by the social meanings individuals attach to particular physical and mental impairments.

(Albrecht and Levy, 1984, p. 14)

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The study of disability situated in family contexts requires the consideration of at least two interwoven family levels: the internal and the external one.

The *internal level* concerns the symbolic, interactive and developmental processes that allow families to re-organize when facing the critical event of disability. Disability can be defined as "critical" in the sense that "the usual ways of family functioning become useless and adjustment processes need to be activated" [authors' translation] (Fruggeri, 1998, p.128). The *external level* refers to the myths and social beliefs that are responsible for amplifying (or reducing) the perception that individuals and families have of persons with disability (Sorrentino, 2006). This level cannot be considered as separate from the first one, as it regulates and contributes to the definition given by family members to the traumatic event. The adaptation processes of families with a member with disability require, therefore, the consideration of both these levels, which should be considered as complementary.

The way in which internal and external levels interlock becomes particularly evident when families get in contact with social agencies. Coping with the disability of a member, especially in the case of children, requires the families to construct a prolonged and tight texture of connections with the services, and specifically the services for education and rehabilitation programs. The construction of this relationship can be considered as developing through a *triangular dynamic* in which the protagonists are: the families, the member with disability, and the educators/professionals working in the services. It is in this complex interaction that families and services build their reciprocal representations and define the nature of their relationship.

In this paper we want to explore the characteristics of the relationship that the educators of educational/rehabilitation services, the children with disability and their family members co-construct over time, and the aspects that can either favor or obstacle the development of family resilience.

### The family dynamics when children have a disability

The studies on families' representations and beliefs when facing critical events (Reiss, 1981; 1971; Walsh, 2003; 2008; Wright, Watson, & Bell, 1996) have shown that family members build and share representations that guide them in the interaction with the broader external environment, allowing them to become more or less "resilient".

The notion of resilience is intended here as the ability to "withstand and rebound from crisis and adversity" (Walsh, 1996, p. 261). The ways in which families confront and manage critical and stressful events of life and effectively reorganizes and moves forward with life will influence the immediate and long-term adaptation for all family members and for the family unit. Reiss's works on *family paradigms* (Reiss, 1971, 1981) have

demonstrated how a critical event or a disruptive transition can catalyze a major shift in a family belief system, with reverberations for immediate reorganization and long-term adaptation. Moreover, family perceptions of a stressful situation, or transition, intersect with legacies of previous experiences in the multigenerational system to forge the meaning the family makes of a challenge and its patterns of response (Carter & McGoldrick, 1989).

Recent studies (Bedin, Benincà, & Mosconi, 2008; Sorrentino, 2006) have pointed out that the families in which a member with disability is present show functioning processes similar to those of normative families; thereby confirming that it is not the *event* of disability *per se* that affect the family adaptation process, but it is rather the ways families make sense of a critical situation and endow it with meaning that is the core aspect for family resilience (Rolland, 1994).

# The "implicit theories" of professionals

Professional encounters, such those between families and social agencies, are communicative and interactional processes through which participants build identities, relations and social realities starting from their reciprocal representations (Abric, 1994; Borghi, Chiari, & Everri, 2007; Pearce, 1994). The representations of educators working with disabilities originate and develop as part of the same socio-cultural context and organization; in other words, they become to share *implicit theories* (Fruggeri, 1998, p.165-166), that is, pre-suppositions and concepts that guide educators' actions and that are not part of formal levels of knowledge. The fact that educators are largely unaware of these theories or premises drives them toward the creation of possible prejudices (Cecchin, Lane, & Ray, 1997) that are activated in the interaction with the others and that contribute to the formation of opinions, perceptions and actions. In order to identify and control them in the course of interactions with both clients and family members, educators should practice a reflexive internal process, which "makes them aware of the effect of their theories, emotions, moods, and actions on clients and their proximal relational contexts" (Boscolo & Bertrando, 1996, p. 23). When educators develop such self-reflexive competence, they can also focus on the characteristics of the relationship with the clients and work in the direction to build an interactive context in which each family member has the possibility to develop and increase his/her own resources. In such relational approach, the educators' acquired technical competences are not left in the background, but they are rather integrated within a more comprehensive professional training and practice, in which both the technical and relational expertise are relevant and interdependent. In this line, educators do not apply protocols, but they rather "observe themselves" while interacting with the others, letting the people's resources emerge, instead of intervening to substitute to the significant others as.

The relational approach to educational practices and intervention represents a way to move beyond a paradigm in which the educator's role is only intended to reply to the clients' needs and to fix "something lacking". Indeed, such perspective reaffirms that the educators trigger and *facilitate* the development of processes in which individuals are acknowledged as responsible, participant and active agents of their wellbeing. The family system is considered as one of the primary and relevant contexts for the clients' wellbeing; and the responsibility assumption for coping with the needs of clients and family members is favored, in order to avoid the perpetuation of dependence from the services and to readdress to them the necessary competency to evolve toward a new organization. Only in such a way, a genuine *co-evolutionary* process of change and intervention can be activated: educators, clients and family members are all active *co-author* (Goffman, 1981) of their change and wellbeing (De Bernart, 1996; Fruggeri, 2008; Fruggeri & Matteini, 1998).

# Research study

#### Aims

In this work, we intend to explore how families and professionals reciprocally co-construct the meanings that contribute to the definition of the nature of their relationship. We will depict the different nuances that characterize the relationship between families with a member with disability and educators that work both in home-based rehabilitation projects and after school educational centers. Three main goals guide this work:

- a) the identification of the resources that family members activate to cope with the disability of one child;
- b) the exploration of family paradigms and representations of the educational/rehabilitation services at home and in the afternoon centers;
- c) the exploration of educators' representations of families having a child with disability and the way in which these premises guide educators' everyday professional practice.

#### Methods

### Participants and procedure

Twenty-two educators from Emilia Romagna and Toscana were recruited for this study. The majority were females (Females n = 21, Males n = 1), the mean age was 33 years (range 25-51), and they had worked in the edu-

cational/rehabilitation service, where they were recruited for the study, for a mean period of 2 years. All educators got a degree in educational or psychological science. They also had previous work experiences in other social and educational services not only focused on disability but also on childcare. Educators had been in contact with the parents of the children with disability for an average period of 1.6 year.

The services have a "cooperative structure", that is, educators are also members of the board, and they offer both home-based and residential educational and rehabilitation programs for children with disability until they are 18. All educators participated on a volunteer base.

Six families were contacted through the coordinator of the educational/rehabilitation services to carry out a video-recorded family interview in their homes to which all family members were invited to participate. These families not only benefit of the home-based program but they also have a regular access to the service structures, where children attend afternoon activities. Parents had attended the services from 3 to 6 years (M = 4.3).

Some parents had developed a confidential relationship with the coordinators of the structures, which allowed the researchers to get in touch with them. However, only three families accepted to participate and gave the assent to videotape the family interview. In two families also the children with disability were present, while in the other parents decided not to involve the child, thus the interview was carried out only with parents. Two families had a two-parents household structure and one was a stepfamily: the mother got married for the second time after her husband's death. All families had Italian origins. In two families, the child with disability was the second born and in one family he was the only child; two were females and one male, all children were in the age range from 9 to 15 years.

### Instruments and procedures

Two qualitative instruments were used for this research: focus group and family interviews.

As for the *family interviews*, a researcher and the coordinator of the service joined the families in their homes. The coordinator introduced the researcher and briefly explained the procedure for the video recording, specifying that in each moment they could stop the interview if they felt uncomfortable for any reason, then she left the researcher alone to conduct the interview. All the interviews lasted one hour and a half; only in one case an interview lasted longer (one hour and forty-five minutes) as the mother asked for more information about the research aims and procedures. The family interview presented a low structural level and was based on a technique intended to solicit the emergence of the different points of view (Everri, Alfieri, & Molinari, 2009; Molinari, Everri, & Fruggeri, 2010). After the presentations, the interviewer started asking questions intended to

explore the re-organization processes activated by the critical event of disability. The first question was addressed to the mother and it was about the way she discovered her child disability. All members were also invited to express their point of view about that event. In this phase, particular attention was then given to the exploration of the family resilience, in terms of emotions, critical and positive moments, and resources activated inside and outside the family, since the communication of the child disability. The interviewer stimulated the discussion and confrontation among the members on the same topics and let them debate, keeping a peripheral position from time to time. Afterwards, the interviewer guided the discussion on the second topic of our interest: the relationships between the families, the services and the home-based educators. She started asking the following question: "if you think of a metaphor about the relationship between your family and the service, what would you say?". The interviewer let each member think individually at the metaphors, and then she asked to describe them.

To sum up, the thematic areas explored during the family interviews were:

- a. the resources activated to cope with the disability of the child (family resilience);
  - b. the representations of the services and educators;
- c. the characteristics of the relationship among educators-children with disability-family members, through the use of metaphors.

Three *focus groups* (two with seven participants and one with eight participants) were conducted by two researchers: one was in charge of asking questions and coordinating the interactions among the participants, while the other was videotaping the interactions and taking some notes about the emotional and nonverbal aspects of interactions. The focus groups explored the following thematic areas:

- a. the educator's role expectations, and the needs and demands of families with children with disability;
- b. the characteristics of the relationship among educators-children with disability-family, through the use of metaphors;
- c. the realization of a project that include both the children with disability and the other family members.

## Analysis of the collected material

All the interviews and the focus groups were transcribed verbatim and a content analysis was applied to the focus groups. The support of the software for textual analysis, Atlas.ti 6.2, allowed us to quickly identify recurrent thematic categories.

The table below (Table1) illustrates the thematic areas explored, the categories identified and their frequency both in the three families and in the 22 educators.

Table 1. Categories used for the content analysis of family interviews and focus groups and the corresponding frequencies.

	Macro-thematic areas	Categories	Sub-categories	Frequency (n)
			Emotional	3
Family interviews	Family resources	Internal	Material	0
		External	Emotional	0
			Material	3
		Educators' and	Positive support	3
	Relationship characteristics	services' repre- sentations	Negative support	0
	(Educator-child with disability-		Separation	0
	family members)	Metaphors	Substitution	0
			Collaboration	3
	Macro-thematic areas	Categories	Sub-categories	Frequency (n)
Focus groups	Representation of the families	Positive	Resources	2
		Negative	No resources	20
	Educator's role expectations	Supportive	Friendship and care	4
		Irreplaceable	Burden	10
		Substitutive	Parenting practice	6
		Collaborative	Accompaniment	2
			Separation	9
	Relationship characteristics (Educator-child	Metaphors	Connection	4
		-	Substitution	8
			Collaboration	1
	with disability- family members)	Intervention	Individual	18
		projects	Family members' inclusion	4

Family interviews were analyzed considering both the contents emerged during the discussion and the characteristics of the interaction.

## Results

The qualitative analysis of the contents emerging from the focus group and family interviews allowed us to depict a multifaceted "picture" of the triadic relationship between families, children with disability and education-nal/rehabilitation services.

## Family interviews

The analysis of the three family interviews, allowed us to indentify two main topics: a) the *resources* that the families activated to cope with the

critical event of the disability and b) the *representation of the relationship* with the educational/rehabilitation services.

In line with the literature, in all families the mothers have a central role during the reorganization process to face the event of the child disability. This has also implied for some mothers to quit their jobs and totally dedicate to the care of their child.

I've always done this stuff on my own. I always do this stuff alone and none knew anything, even my husband as it was a very difficult thing to stand, as I knew I would have give bad news to my parents and husband. It was very hard to tell them these issues. Then I took my taxi alone and I went to visit the neurologist and then I told it to them lately (C1)

I always have to be present for his crisis. If I'm alone with him I cannot do everything as I've always to be with him (B1)

In my case my husband and I decided that I had to quit my job to take care of our daughter at home (A1)

The other family members acknowledge the mothers' fundamental role and participate to family routines mainly to provide practical support. Fathers tend to dedicate their time to practical activities with the child with disability such as, playing together, watching TV and picking up them from school.

My mother has a lot of strength, a big heart and motivation, everything rotate around her (B4)

I feel I'm part of this family, I try to collaborate as a father, as I'm not the father, but I take the responsibility for everything, also with G. I do all that is in my possibility. Sometimes I pick her up from school, then I take her to the swimming-pool (C3)

(...) when I come back from work, I spend some time with R., we play together or watch the TV, then I take him to bed (A3)

It is also interesting to note that in the families where older siblings are present, parents have prevented them to be overwhelmed by the caring routines of the child with disability. Siblings report that they have never had problems in making their own choices, such as going out with friends or deciding to move to another city to go at the University. These aspects has a positive effect on the relationships among siblings as well, as older siblings could both preserve their own "life space" and spend part of their free time sharing fun activities with their brothers/sisters with disability:

Well, I've always been free of making choices, I chose the university and it was not for my brother's disability but rather for other reasons (B3)

When I come back from the University during the week-end, G. is very happy to see me, she looks for me and I'm more relaxed and I know I can dedicate to her (C2)

I never had problems to make my own choices, and I didn't have any particular obstacles or anything different from those of my friends (C2)

then, sometimes at night R. looks for me, then I go in his bedroom and we listen music on the IPOD, or sometimes, he gets close to me and then we play games on the computer together (B3)

Another aspect explored with the family interview concerned the *representation of the relationship* with the educational/rehabilitation services. Family members report that the support offered by the services, specifically the relationship with the home-based educators, is fundamental for dealing with everyday and practical issues. Again, the mothers emphasize this aspect and underline that the presence of the educator helps them to have more time for themselves.

When the educators comes at home she helps me a lot to do my own staff, otherwise I've always to be involved with R. (B1)

(...) they are very important especially for some disability, but one hour of therapy it is not useful, but more help is needed (C1)

On the one hand they should work on child competences and others focused on the everyday activities that allow you to have more time for yourself (A1)

Family members also report that the decision of a common line should be pursued and shared with the educators. This proposal is characterized as a request to be involved in the definition of their children's treatments:

It is important to have the same line of thoughts, if I do not believe in something also the educators should not do that (...) we decide everything together (C1)

I always talk with educators and use the information they give me. However, if they decide in a way and I agree, I do the same, but if I do not agree I say, I've some doubts, I'll do this. It is a kind of collaboration, they can take info from us and we from them. It is something reciprocal (A2)

They help us for reaching some goals. The educators should follow our daughter in the rehabilitation steps and the also involve us (C1)

The services should propose some options as support, and we should decide to use them or not, I mean, they should make some proposals and then discuss them all together (B2)

It is also noteworthy that during critical moments family members do not expect emotional support from the services, but they rather search it in the extended family network:

We need to find a force inside, family is really important, all the family net is relevant. We need to be strong (B1)

Grandparents are really important (...) my mother and my sister were very close to me after G.'s birth (A1)

My parents are still doing good, se we relied on them during sad moments (C2)

In order to deepen the representation that families have of the relationship with educators, we asked them to describe it using a metaphor. Most of the images individuated by the family members underline the aspect of "collaboration" with the services: a series of boxes all connected, people in the same boat rowing together and people standing side by side. The child with disability is located in the middle between the service and the family, two contexts that always are in communication one with the other.

G. is at the center and family and services on the side, but the family is pretty close to the services. She is at the center and we are on the side. But we communicate and collaborate (A2)

The educational treatments are a box of resources. (B3)

The biggest box is the family" (B2)

Then inside the smaller are the other associations and the other treatments (...) there is always a communication between them, the experts say what is the best to do (B1)

I imagine a tandem bicycle or two rowers in a boat rowing together in the same direction (C1)

A parent is always there, the educators do not substitute, I mean there is always a close network and a great collaboration (C2)

### Focus groups with educators

The thematic areas that emerged from the content analysis of the focus groups with the educators pertain: a) the representation of the families with a child with disability, b) their role expectations, c) and the description of the relationship characteristics between educators-child with disability-family members.

As for the *representation of the families*, educators share the idea that families with a child with disability have to face many difficulties and deal with everyday burdens. Educators perceive parents as lonely and isolated, especially mothers, who are defined as needy of support and with a scarce social network:

These parents are alone, they should be part of associations, but often they aren't (...) The problem is the parents' loneliness (E7)

The mother is really alone, she should have someone to take care of her (A1)

A big pain and grief, I saw mothers pressed under this burden (EM2)

In this line, educators believe they are expected to be a fundamental resource not only for their child, but also for the parents. On the one hand, they acknowledge that this is integral part of their role, but on the other, they feel the burden of being considered as "irreplaceable". An educator effectively uses the metaphor of the "Saint":

In my case, I'm kind of a Saint, and this is a problem as when I'm not there, the mother keeps him at home, besides, we became friend and this help me, as I can better deal with my schedule (...) and when she is down she takes her Saint and looks at it (A1)

For sure from the parents' part I noticed this tendency, I mean none is irreplaceable, but I noticed that parents tend to always ask for the same educator (A2)

Others stress the fact they are asked to go beyond their role competences as educators, "taking advantage" of the fact they are available in the families' homes during the whole week. Indeed, educators feel to be expected to offer both material and psychological support to all family members; this request is evaluated as negative and makes them to feel overwhelmed.

The family can take advantage of the situation, asks for something both material and psychological that goes beyond your role and it is a psychological burden that doesn't work and it is added to all the rest (EM2)

Educators, therefore, seem to orient their professional practices toward the "compensation" of these needs, sometimes substituting to family members. This aspect has also relevant implication for the definition of the boundaries of their *identity* as professionals. They refer to be often perceived as "friends" more than experts, and this is evaluated as negative:

I developed an intimate relationship with the family and it is difficult as it is not good, because one become one of the family when is in the family (EM1)

They see the educator as a friend, a support and someone to share the problems with (E7)

Only few educators stress that their role consists of "accompanying" family members along their life-course. This entails the idea that a confident and intimate relationship with family members is integral part of their professional role, but they consider themselves as "competent companions" of parents instead of their substitutes.

I see that we accompany them, we accompany them throughout their children's life course, we are point of reference, as we work for the continuity, then we work to build a continuity and being important person to be confident with, as sometimes we are both at school and home, or we do some activities during the summer, for Christmas also we have some hours to do (...) I think I'm the person that should accompany them (EM1)

After exploring the representations of educators working in close contact with families during home-based programs, we wanted also to define the

characteristics of the relationship between the families and the services offered to children with disability outside the family. We then asked the educators working in the afternoon centers for after-school activities to describe the relationship occurring between them and the families.

Most of the educators see a clear-cut separation between the center and the family context; children are literally "transferred" from one place to the other.

The relationships are child-center and child-family (AM2)

We usually work separating what we do at school with children and what we do in the families. For instance, once they pick up children from school and they go home is different from when they stay in our centers. At home parents have their own idea about how to deal with their children (EM2)

Educators acknowledge that the two contexts require them different competences, as parents are not present in the centers. The contact with the parents (usually the mother) occurs every day; however, the communication with them is often formal and disengaged. This aspect stresses, once more, the idea of separation:

We use the journal where we inform of the activities, we exchange information and it is only that with the mother (...) (L9)

Sometimes we communicate using the journal, not even with the phone (B2)

*To me it is more a formal relationship on the door of the center (F2)* 

I'm involved only for formal communication, not for birthdays or to have a pizza (...) we have a communication with parents when they come and leave, we see each other everyday (G3)

In order to have a clearer picture of the characteristics of the relationship between the educators and the families, we also asked them to think of a metaphor that could better represent the relationship between themselves, the child with disability and the family.

Both the home-based educators and those working in the centers propose similar metaphors, such as a "bridge" or a "boat" that transfer passengers from one coast to the other of an imaginary river. Others suggest the image of a "ferry-man" or a "wire":

In my opinion the educator is a bridge between families and educational context, this is natural (G3)

I think I'm a kind of a ferry-man (C6)

I also think that there are two worlds connected by a wire (B4)

In these metaphors, the educators seem to be in a position that favors the connection between the service and the family, supporting or helping the child with disability during his/her life-course (to "cross the river") or critical events

of life (to "solve a puzzle"). In these cases, the primary attention of the educators is on the dyadic relationship with the child:

A boat that transfer the child and the mother and wait for them. The river is the child's life and the boat helps him to cross it (F1)

I think it like, when you have to solve a puzzle: the child has different pieces in front of her and she needs help to put them together. My role is to help her to do that and help her to get organized in her everyday life (A4)

Only one educator introduces an interesting image that includes the whole family. She imagines of being a "bird" that flies together with the family members, *accompanying* them in a "journey" in which they trust each other and "fly" side by side:

I feel I'm a seal that travels with the family and P. Someone who accompanies them, someone they can trust and that they can trust (B2)

The last aspect considered was the request to *plan a project* intended to involve the whole families. We solicited the educators to realize projects addressed to both the child with disability and the family members. Interestingly, the projects they proposed reaffirm the need, from their points of view, to keep a separation between their work with the child on one side, and the family members, on the other.

Some educators stressed that the parents' presence during home-based programs can be negative and menace the efficacy of the treatment. Specifically, the presence of one parent prevents the educator to have an authoritative role with the child, thereby becoming an obstacle to her work. They think, however, that family members should be involved, but in separated moments from those dedicated to the child:

In my opinion you should follow two parallel paths. For the goals of our programs, it is useless the presence and it is even bad. I have many problems with J. when his mother is present, as the child scream and I cannot impose myself. Then it would be nice to have specific moments with the families, but they should be different from those we usually do and they should be separated (A1)

Others, again, reinforce the idea that family members should be part of the treatment programs, but they acknowledge the lack of procedures that can allow them to build a connection with parents and siblings of children with disability. This is considered a critical aspect as it is a source of anxiety, and contributes to make them feel as "invaders" of an imaginary space that is usually occupied by parents. An educator specifies that she planned and applied, together with a psychologist, an educational training for parents, but

she found many obstacles for its realization. She felt unprepared to deal with such a treatment and she felt the mother perceived it as a real invasion.

I don't know (...) I should maybe see them all together, but then I don't know how to create a link with them (I3)

The psychologist told me that I had to work on family relations, I considered it as a bit beyond my job, and it caused me a lot of anxiety. The treatment consisted in doing things together, propose an alternative educational style, so we had to plan common moments with the mother and that was very difficult, she my presence was an invasion, she couldn't stand me anymore, it was a total invasion (M8)

Educators are aware of the aspects that can obstacle a more complex and effective program of intervention with family members. In fact, they acknowledge the necessity for the parents of the children with disability to be *accompanied* since the first years of the child and make them more competent and responsible of their children growth.

I really would like that these parents are accompanied and actively participate to their children activities since the first year of their child birth, and that we could have quiet meetings with neuro-psychiatrists, therapist, teachers, and educators to realize a real project of life. In my opinion parents could be followed, accompanied and helped more only if we were more honest with them (P1)

The Ausl should take care of the whole family even before the person with disability, as it is the child condition that has an effect on the kind of rapport, so maybe the service should be more open in this sense (Ma3)

Once they are inquired about the possible path to realize such projects, they suggest solutions based on a kind of *compromise* between the services' programs and the needs of the family. In this sense, it is still the service that is responsible to make the decisions for the treatments.

I'd like to see all them at home for one week and be a fly, a kind of hidden observer. Then once we have to prepare an educational program we could say, we do this in this way and you do it in another way, we have to do it in the same way. Then maybe it is their way that is the right one, but at least it can be considered as a way to understand something (AM3)

#### Discussion and conclusion

The examination of the representations of both families and educators allowed us to have a double perspective on the same object, that is, their relationship. It was interesting to note that the families and educators' reciprocal representations only partially overlap.

From the educators' part emerges that it is still a hard work to shift perspective from seeing families as "damaged" to viewing them as "challenged". This representation guides some educators toward professional practices oriented more toward the substitution rather than the activation of families' resources. This is visible in the moment when educators perceive the mothers as weak and with a scarce social network and think to be expected to provide emotional support, thereby driving them to burn out. The mothers, on the contrary, declare to expect that educators provide them mainly with material support, as the emotional one is searched in the extended family network. The educators' implicit theories oriented to the substitution entail the idea that families represent a limit for an effective realization of a rehabilitation/education treatment for children with disability. In various parts of the focus group, educators underlined that when they work at home with the child with disability, the presence of parents become an obstacle, rather than a resource, and they can hardly handle their presence.

As for families, in general they evaluate the relationship with the service as a fundamental resource for the "survival" of the whole system, not only for their children. All the three families proposed metaphors that recall the idea of *collaboration* with the service. Some members also claim that more collaboration should be offered especially through the inclusion of their participation and the consideration of their opinions to plan the rehabilitation programs of their children. In other words, what families seem to ask is the possibility to be acknowledged as *competent collaborators*, instead of someone to exchange information with, about the treatments of the children.

Interestingly, also some educators share the same representation reporting examples of collaboration with the family. However, educators have and idea of collaboration that tend to re-propose a representation of the family both as a resource at the "service" of the educators and as context used to *facilitate* their professional practice. In other words, they see the relationship with the families as a kind of *unilateral collaboration* (Fruggeri, 1998) in which family members are involved to exchange information and assign prescription in order to accomplish an effective treatment for the child.

In conclusion, enlarging the lens of observation on the triadic dynamic which take place among families, members with disability and services, we can speculate on the fact that *resilience* is a process that emerges not only from the families capacity for self-repair, but also from educators' relational competences. Keeping this in mind, allows professionals to "adjust" their treatments not only identifying the family with a member with disability as a *resource* to strengthen the efficacy of the rehabilitation treatment but also to *promote* those aspects that allow family members to develop the capacity of self-repair. This implies to develop a self-reflexive practice that allows educators to abandon models that consider professionals as the experts who know how to "fix" damages and "restore" conditions of normality. We rather

propose to take into consideration a *co-developmental* model in which *both* families and services collaborate to the planning and realization of specific treatments. In this line, we advance the idea that services specialized in educational and rehabilitation programs for disability, should be reorganized being aware that the "critical event" of disability should not be intended as a permanent condition for families. This event should be rather re-defined as a *transitional* moment in which services can collect family members' needs and requests with the intent to activate family resources, activate positive changes and long-lasting transformations.

We are aware that this study is only a snapshot of a more complex and articulated picture. The possibility of conducting interviews with a larger number of families and the administration of self-reports intended to focus more specific aspects related to disability such the as co-parenting dynamics, could open further path of work. Moreover, the possibility to realize longitudinal studies to depict the interactional *process* that maintain family resilience considering both the family internal dynamics and the relationships with services but also school, could further illuminate on the complex triadic dynamics among families, children with disability and services.

#### References

- Abric, J. C. (1994). *Pratiques socials et representations [Social practices and representations]*. Paris: PUF.
- Albrecht, G. L., & Levy, J. A. (1984). A sociological perspective of physical disability. *Advanced Medical Social Science*, 2, 45-106.
- Bedin, M., Benincà, A. C., & Mosconi, A. (2008). La "normalità" della famiglia "disabile" [The "normality" of the "disabile" family]. *Terapia Familiare*, 86, 25-53.
- Borghi, L., Chiari, C., & Everri, M. (2007). Genitorialità diffusa e sviluppo dell'intersoggettività nella relazione tra nuove famiglie e servizi per l'infanzia. Report di ricerca [Parenting and widespread development of inter-relationship between the new families and child care. Research reports.]. Comune di Bologna, Settore Istruzione.
- Boscolo, L., & Bertrando, P. (1996). *Terapia sistemica individuale [Individual systemic therapy]*. Milano: Raffaello Cortina.
- Cecchin, G., Lane, G., & Ray, W. A. (1997). Verità e pregiudizi: un approccio sistemico alla psicoterapia [Truths and prejudice: A systemic approach to psychotherapy]. Milano: Raffaello Cortina.
- Carter, E., & McGoldrick, M. (1989). *The family life cycle: a framework for family therapy*. New York: Gardner Press.
- De Bernart, R. (1996). I rapporti dell'istituzione terapeutica con le famiglie ed i servizi territoriali: problematiche attuali e strategie di cambiamento [The institution's therapeutic relationships with families and community services: current issues and strategies for change]. In P. Masoni (a cura di), La riabilitazione dell'adolescente nella comunità terapeutica. La patologia mentale [The rehabilitation of the adolescent in the therapeutic community. The

- severe mental disorder: New methodological trends]. Lucca, Italy: Edizioni Del Cerro.
- Everri, M., Alfieri, E., Molinari, L. (2009). Osservare le microtransizioni familiari in adolescenza [Observing family microtransitions in adolescence]. In L. Fruggeri (a cura di), *Metodi osservativi per le famiglie*[Observational methods for families] (pp. 95-138). Roma: Carocci.
- Fruggeri, L. (1998). Famiglie: dinamiche interpersonali e processi psico-sociali [Families: interpersonal dynamics and psycho-social processes]. Roma, Carocci.
- Fruggeri, L. (2008). La famiglia di fronte alla disabilità: processi evolutivi e strategie di coping [The family in front of the disability: Developmental processes and coping strategies]. *Pensieri e Proposte*, 38-43.
- Fruggeri, L., & Matteini, M. (1988). Larger systems: Beyond a dualistic approach to the process of change. *The Irish Journal of Psychology*, *1*, 173-182.
- Goffman, E. (1981). Forms of talk. Philadelphia: University of Pennsylvania Press.
- Molinari, L., Everri, M., & Fruggeri, L. (2010). Family microtransitions: Observing the process of change in families with adolescent children. *Family Process*, 49, 236-250.
- Pearce, W.B. (1994). *Interpersonal communication: Making social worlds*. New York: Harper Collins
- Reiss, D. (1971). Varieties of consensual experience. Family Process, 10, 1-28.
- Reiss, D. (1981). *The family's costruction of reality*. Harvard University Press, Cambridge, MA.
- Rolland, J.S. (1994). Families, illness and disability: An integrative treatment model. New York: Basic Books.
- Sorrentino, A. M. (2006). *Handicap e riabilitazione. Una bussola sistemica nell'univer*so relazionale del bambino handicappato [Disability and rehabilitation. A systemic compass in the relational universe of handicapped child]. Roma: NIS.
- Walsh, F. (1996). The concept of family resilience: Crisis and challenge. *Family Process*, *3*, 261-281
- Walsh, F. (2003). *Normal family process. Growing diversity and complexity*. New York: The Guilford Press.
- Walsh, F. (2008). La resilienza familiare [The family resilience]. Milano: Raffaello Cortina
- Wright, L. M., Watson, W. L., & Bell, J. M. (1996). *Beliefs: The heart of healing in families and illness*. New York: Basic Books.