

“Being siblings of...”

Psychological support for siblings of people with serious disabilities

2012 EDITION

Context and general goals

Without a doubt, the family is the most important place for socialization, growth and development of the personality, and the expression of attitudes and habits.

The family is not a static, closed unit, but a dynamic and complex system that influences and is influenced by many factors, such as social, cultural, and historical development, as well as personal events and individual changes.

The most important changes in young people manifest during the transition to adolescence, when changes occur not only physically, but also cognitively and socially, and the family system must adapt to new situations. It is a period when conflicts between parents and children generally increase, and both the nature of parental authority and ways of relating change.

Another important variable is the number of brothers or sisters living with the child, since this determines the horizontal dimension (among equals) that the child experiences within the family context.

It is therefore easy to imagine the complications that arise within a nuclear family when one of its members is disabled.

The siblings of the disabled person live with a very difficult situation. It is likely to involve a certain level of solitude connected to the reality of living in a family that must deal with a handicap without sufficient space to handle it within the family, and so attention is mostly dedicated to the disabled child. This solitude also touches the world of his peers, where it is difficult for this kind of problem to be understood and dealt with.

These kids also receive less attention, are discussed less in the literature, and are given less consideration with regard to activities. In fact, when we speak about "family", we mostly mean the parents, and the activities concentrated around them.

The siblings of people with complex disabilities, who are the target of this initiative, share certain difficulties:

- they are often on the margins of parents' attention and the entire family context, which is focused on the needs of disabled siblings;
- on the other hand, they are at the center of the expectations of their parents, who often have a great deal invested in them; this highlights the difficulty of discerning their true needs and desires
- they have difficulty expressing their emotions and needs, both within the family context and their peer group, who find it difficult to share or understand their level of responsibility

Nevertheless, at some future point, the siblings of people with disabilities will, realistically, need to care for their disadvantaged siblings—an event often characterized as happening “sometime in the future” and thus not always elaborated with sufficient clarity.

Considering that the sibling relationship is the longest that a person can experience (Cicirelli, 1995), brothers and sisters have many questions that need to be answered. The goal of this project is to put the spotlight on the siblings of people with serious difficulties, their experiences and their everyday reality, but also to ensure that their sense of isolation is lightened by the presence of peers with similar difficulties, with whom they can communicate and enjoy pleasurable activities.

Project Description

The project came about as a result of a comparison of experiences by families of children with severe disabilities, which revealed the insecurity and fear inherent in problematic relationships with their healthy children. This revealed, therefore, the need to understand how to properly deal with them and help them accept their family members' illness. In fact, the scientific literature describes of a number of typical characteristics of **“siblings of...”**: shame, a strong sense of responsibility, containment of anger and emotions. But there are no solid and comprehensive proposals to give these kids a path to deal with their peers, so they can share moments of happy and relaxed interaction in which they can take the often-denied position of center stage.

The many years of experience in social education held by the participants in this project led to the identification of the following issues as particularly important: the need for a path to independent education and the need for secure and rewarding socialization experiences. The project is intended to address the stages of infancy and adolescence, phases of passage or transition characterized by a sense of risk and uncertainty, where kids are faced with many challenges in building their own identity. For children living in difficult situations on the personal, family, and social levels, the

criticality of the moment is further amplified. The hyperprotective family of children with disabilities/illnesses, the difficulty of parents faced with a child with special needs, and the problems of adult family members create situations where healthy children and young people struggle to find appropriate paths of growth, attention, and affection.

The project includes a series of discussion meetings that are part of a path of play, with the goal of highlighting the issues related to the condition of being siblings of... and to ensure that each participant can recognize in the other a partner whom he can identify with and count on to be able to share his experiences. This path aims not only to give an immediate response to the tangible discomfort of the individual, but also to prevent the difficulties that can arise during the transition from adolescence to adulthood, both socially and in the family context.

Overall Objective: To contribute to the cultural and psychological growth of children.

Specific Objective: To facilitate the expression of the hardships faced by healthy siblings and to help them develop a healthy awareness of their experiences through reading, recognition, and reworking of their own emotions by starting a constructive exchange in a peer group that experiences the same shared reality, in order to create psychological well-being.

Activities:

- Monthly meetings (evenings out, half- to full-day outings) with the sibling group under the guidance and supervision of a psychologist and two specialized educators.
- Evening meetings, held quarterly, with the parent group and expert consultants on family dynamics in the context of disability, who will show parents the main difficulties in family relationships, specifically with regard to the context of the healthy sibling/disabled sibling, providing parents with the knowledge, tools, and strategies to better manage relationships with their healthy children.
- Group activities designed to elicit specific behaviors and provide keys to their management (for example, aggression/containment, excessive responsibility/awareness and management, shame/ability to express, etc.).
- Individual interviews with families to discuss the results of the project's scientific observations at its beginning and end and during the activities, focusing on key strengths and weaknesses of the son or daughter.

- Consultations with experts in difficult family dynamics (disability), study of aspects of communication and relationships, and possible strategies to be adopted.

Expected Results

- ❖ expression of feelings and needs
- ❖ facilitated communication and debate on the issue of being brothers/sisters of people with established disabilities
- ❖ acquisition of relationship knowledge and competencies
- ❖ greater self-awareness
- ❖ strengthened self-confidence
- ❖ enhanced self-esteem
- ❖ growth and establishment of trust and respect between parents and children
- ❖ parent awareness of the needs of their children
- ❖ group creation among families

Collaborations and partnerships with other groups:

Associazione Prader Willi, which offers support to families of patients with Prader Willi Syndrome, has worked on the Being Siblings of... project through partial funding of some activities, and continues to work with the participation of the three families associated with them.

Dynamo Camp Foundation, which works with Ring 14 to make their facility available to disabled persons for one week during the summer. In cooperation with Ring 14, the Foundation organizes psychologists and educators participating in the project, recreational activities, and training sessions specifically for building an ad hoc vacation for siblings of...

Social Sustainability

The project is a “**best practice**,” reproducible in different areas and contexts. Ring 14’s intention is also to promulgate the encouraging results obtained with the project to stimulate other organizations to implement initiatives and specific services for the siblings of people with disabilities.

Economic and financial sustainability

The project Being Siblings of... has been managed and financed by Ring 14 since 2009 through donations from private parties and the collaboration of organizations and institutions as well as participating partners.



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DA MALATTIE GENETICHE RARE - ONLUS.

IMPEGNO, SOSTEGNO, FUTURO.

Care has been taken to initiate long-lasting collaboration with other associations and foundations to ensure the project's financial sustainability.