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לשינוי באיכות חייהם של אנשים עם מוגבלויות

Beit Issie Shapiro

Changing the lives of people with disabilities

בקמפוס וילי וסיליה טראמפ

On the Willie & Celia Trump Campus



Special Siblinghood

Brothers and Sisters of Children with Developmental Disabilities

Beit Issie Shapiro's Programs for Intervention

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In memory of Tamas and Veronika Hartman

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Beit Issie Shapiro impacts over 30,000 people every year and is Israel's leading innovator of new therapies, changing attitudes in society, advocating for better legislation, and sharing knowledge internationally through research and training.

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Special Siblinghood

Summary

This publication relates to programs for brothers and sisters of children with developmental disabilities, such as Cerebral Palsy (CP), autism, intellectual disabilities, various syndromes, etc.

Background

1. Special siblinghood in the familial space

The birth of a child with disabilities is experienced by families as a crisis, forcing them to face difficulties and challenges that require each family member to rearrange many areas of their lives. Parenthood, as imagined before the birth of the child with disability, changes. Doubts, unfamiliar situations and fears are part of the experience of special parenthood.

Parenthood and siblinghood are interwoven and influence each other to a great degree. The presence of a sibling with a developmental disability influences the development of each child in the family. This influence may be a source of difficulty and distress, as much as it can be positive and encouraging of growth (Seligman, 1991; Nixon & Cummings, 1999). Research in this field yields inconsistent and sometimes contradictory results. In recent years, prevalent approaches, which are based on theories of personal growth and growth resulting from crisis, point to the fact that siblings of children with intellectual disabilities report of growth more than siblings of children without intellectual disabilities (Vardi, 2005).

As a child with disabilities enters a family, the siblings respond to her and to her needs. Their interaction with their parents changes. In addition, the relationships within the sibling sub-system may also change. For example, the chronological order of birth loses its significance as a younger sibling

developmentally overtakes the older sibling with disabilities and becomes “bigger” and more mature.

The intensity of the sibling connection becomes greater as parents are less available due to the crisis and the great burden of raising a child with disabilities. These erode the parents’ ability to satisfy the needs of all their children.

According to some research studies, many siblings struggle with difficult emotions, thoughts and worries, more than they let show. Feelings of anger and embarrassment, at the root of which lie guilt and shame, may leave the sibling feeling very much alone. The sibling may also experience feelings of compassion, pride and love, which are easier for the sibling to express and for the environment to accept. Other studies show that siblings of children with special needs demonstrate more positive behaviors and interactions than children without siblings with special needs. The positive aspect includes higher levels of empathy and altruism, tolerance of individual differences, greater maturity and personal responsibility (Powell & Ogle, 1985).

Familial and parental variables impact heavily on siblings. The most significant of these are: the level of acceptance, the level of familial solidarity and integration, the effectiveness of the family’s support system and its extent, the family’s type of communication – enabling or blocking emotional expression.

At times, the feelings around them are a kind of a “secret”, and the general goal of the treatment is to resolve and release the energies invested in guarding it. Treatment depends also on the complexity of the problems the siblings experience, their age, their cognitive level, wisdom and insight and the availability of different therapy options.

2. **Special siblinghood in the social space**

Siblings of children with disabilities encounter the stigmas prevalent in society regarding people with disabilities that arise from ignorance, lack of information and knowledge. The

prejudice and the social difficulties in accepting difference force siblings to face challenges, difficulties and complicated emotional experiences. Special occasions, such as birthdays and being out in the public-social space, may cause dilemmas and individual and familial stress.

Siblings cope in a variety of ways: from avoidance (siblings avoid asking friends home) to blunt and aggressive exposure (attacking those who watch them in the public space) or even joining the aggressors (making fun of their sibling along with other children or ignoring her when in the presence of friends).

A person's social intelligence develops, among other factors, as a result of the patterns of his/her interaction with his/her surroundings, and the relationships with other people influences his/her quality of life. The family and the peer group are involved actively and dynamically in the growth and development of the person from child to adult, and to a large degree from his/her personality and behavior patterns in the future.

The siblings' relations with their psycho-social surroundings and their pattern of interaction with peers contribute significantly to their emotional-social development. Bad social relations may delay and disrupt their development. According to various authors, the social stigma emphasizes the social significance of the difference in the eyes of the typical sibling, and the child with a disability makes the family different from other families. This difference may cause difficulties for the siblings, especially if they encounter reactions or questions from their environment that make them feel shame, guilt, hurt, etc. The label that is attached to the family as a whole comes with a social price, and as a result of the stigma, siblings may react with withdrawal, distancing themselves from friends; at times, the stigma may damage their self-image.

The agencies treating the child and the family should provide to each family member the required resources, including an

environment that facilitates optimal growth. This is why interventions that focus on changing the relationships between persons and their social environments, including interventions for changing attitudes and stigmas, are requisite for the improvement of the siblings' quality of life.

Over the years, various organizations developed diverse programs, from individual treatments, through group interventions and group therapy, to community interventions, with the goal of increasing the wellbeing of siblings of children with disabilities.

These programs run the full gamut from short-term supportive treatment, or cognitive behavior therapy, to long-term psychodynamic therapy, from individual treatment to group and family treatment. Research shows that treatments can be combined or only one solution can be selected. The most important thing is to provide a space for expression and sharing (Sloan et al., 1975).

Beit Issie Shapiro's programs for siblings and parents

Beit Issie Shapiro is a family focused center, which works and connects with the circles that surround the child with a disability: the nuclear family and the extended family (parents, siblings, grandparents and sometimes uncles and other family members).

Beit Issie Shapiro provides families with a host of solutions on the individual, marital, familial and group levels, both at its daycare centers – rehabilitative daycare center, kindergartens and special education school – and through its Family Therapy Center for emotional therapy.

Regarding brothers and sisters of children with disabilities, we have developed over the years solutions under two main headings:

A. Solutions for siblings

1. Fun days

In a long tradition, Beit Issie Shapiro hosts siblings for a fun day every year. This enables the siblings to get to know in an experiential way the framework where their siblings attend every day, and find camaraderie with other siblings of children with disabilities. 35-50 brothers and sisters participate.

The fun day comprises several activities:

- Assembly, getting to know each other and breakfast for all the siblings.
- Activity stations: the siblings are divided into groups according to age. Each group participates in activities at three to four stations, guided by students and volunteers. Common stations are: Gymboree, competition games, various arts and crafts activities, makeup and “tattoos”, and an activity with a music therapist. For each child, there is also a “station” where he/she participates in an activity with their sibling’s special education class. The staff is ready for their arrival and is attentive to them.
- Playing and having fun at the pool.
- Lunch.
- Concluding words and saying goodbye.

2. Workshops

A workshop provides the participating siblings with a unique opportunity to get to know other siblings of a similar age, from a slightly different angle. The workshop framework is suited to focusing on specific issues.

The workshops enable the participants to raise and learn about issues that are on their mind in a creative, experiential and fun way, and enable them to relate in an experiential way to situations and personal experiences related to these issues. The workshops provide the facilitators with greater space for action and enable the

participants to go through a process of revealing and processing emotions, helped by the dynamics created at the workshop.

We hold two types of workshops:

- Concentrated one-day workshop
- Three-day workshop.

3. Therapy groups

In a therapy group for children, processes are accelerated in comparison with individual treatment (Barratt & Segal, 1996). The reason for this is the mutual effects participants have on each other, making it easier for them to express behaviors, thoughts, ideas and fantasies.

Beit Issie Shapiro conducts time-limited therapy groups for siblings of children with disabilities. Groups meet for 12 sessions of 90 minutes each. A group consists of 5-8 brothers and sisters. Each session includes an activity initiated by the therapists. The activity functions as an axis around which the children can bring up contents from their internal world, as they reflect off the group mirror. The group relates to each member in a dual fashion. On one hand, as an individual in his/her own right who is separate from their sibling with disabilities, and on the other hand, as a sibling of a child with disabilities. The difference is raised through the group dynamic and interaction.

4. Individual therapy

Individual therapy focuses on the siblings' internal world – their emotions, thoughts and subjective perceptions of the reality in which they live. Individual therapy is conducted through “face to face” meetings to enable the sibling to express his feelings and cope with his emotions optimally. Therapy can help in dealing with issues such as: self-image, handling stressful situations, difficulties in emotional control, problems in social functioning, going through developmental stages and transitions, parent-child relationships and dealing with various crises.

Therapy for young siblings is carried out using two main tools – play therapy and parental guidance.

5. Awareness raising activities at the siblings' educational frameworks

The program for intervention in the siblings' social environment was developed following:

- Requests from parents who asked for our help for siblings who were struggling to find their place within their social frameworks, and in particular at school.
- Recognizing how much influence the social environment and social stigmas have on the siblings' quality of life, and the insight that it is the social environment that should change.

The program includes several stages:

- (1) Establishing trust between the sibling and the professional.
- (2) Getting to know the sibling with disabilities and her educational framework.
- (3) Getting to know the sibling's home room teacher and receiving the school's approval to carry out the program there.
- (4) Developing together with the sibling and the home room teacher an activity program for the class children.
- (5) Carrying out the planned activity for the sibling's class. The activity usually consists of two to four sessions.
- (6) A meeting between the sibling's class and the class of the sibling with disabilities for a joint experiential activity, preferably at a park or a garden or a meeting at home between a group of children from the sibling's class and the special sibling.
- (7) Concluding the activity - or expanding it to additional classes.

B. Solutions for parents on the issue of special siblinghood

Most parents we meet have many doubts and worries around several central issues:

- How to explain the needs of the sibling with disabilities?

- How to allocate the family resources (time, attention, etc.) more equally among the siblings?
- Is it right to burden siblings with more responsibilities and roles than their peers?
- How to respond to negative feelings towards the sibling with disabilities, when they arise?

Several intervention programs for parents were developed around these and other issues.

1. Parental guidance:

Is carried out as a meeting between the sibling's parents and a professional. The session focuses on their uncertainties regarding the sibling and giving parents counseling and tools to better handle their difficulties. The basic assumption in parental guidance is that parents know their child better than anybody else and that they have a significant influence on him/her. Some parents require guidance in how to provide the sibling with the support and solutions he/she needs.

2. Learning group:

Participation in a parent group helps many parents to gain information and share dilemmas they have regarding siblings. The group enables sharing of emotional experiences and learning from the life experience of other parents who deal with similar issues. The group serves as a learning laboratory where parents gain objective knowledge while at the same time they engage in open discourse with other parents. They share experiences and learn from each other different ways of coping.

3. Three session workshop:

At this workshop, parents share experiences and situations from their family life. Emphasis is given to communication within the nuclear family and the various ways in which difference, emotions and the struggles that family members go through can be

discussed. The workshop focuses on the parents' feelings and expectations they have of the siblings.

4. "Peeking into the future" – lecture and discussion with adult sisters:

The seminar "Peeking into the future" enables parents to meet adult sisters, aged 23-25 years old. The sisters relate their life experiences and subjective experiences as sisters to a brother or sister with disabilities during various stages in life – children, adolescents and adults.

The sisters discuss the influence that special siblinghood had and has on them, on their lives, their family life (the family coming together around the special child, or parents divorcing), the "tests" that the sister's potential mates go through – how they respond to and will they accept the sibling with disabilities, and the career choices they made as adults.

They bring attention to the responsible "role" that siblings tend to take on and told about their need to protect their sibling with disabilities. They convey to the parents a message that it is important to encourage the other siblings to play with their friends and follow their interests.

The sisters all said that it is important for families to talk openly with each other.

All concluded that while there is no doubt that special siblinghood was and always will be an important part of their lives, they also emphasized that apart from it they have a full life and a family of their own.

This publication opens a window to understanding the need for programs for siblings of children with disabilities, to support them as they face the uniqueness of their lives.

Parents and siblings face diverse challenges and they need insights and tools to improve their quality of life as individuals and as families.

We hope our accumulated experience and the programs described in this publication will help additional families and professionals in their work with families of children and adults with special needs.