



Children with Special Needs: The Role of the Family

Dr. Tali Heiman of the Department of Education and Psychology addresses an issue of tremendous public interest and importance – helping many thousands of parents and professionals to assist children with special needs in their struggle to become constructive and successfully functioning members of society. Her industrious academic activity take three parallel directions, all contributing to the needs of the community in reaching out to children with disabilities: in research on family coping with the special needs; in a public symposium open to students, parents, practitioners, educators and professionals who daily grapple with the challenge of trying to help; and a course textbook to provide informative and authoritative knowledge on the subject.

Parents of Children with Special Needs: How They Cope

It is widely recognized in research that children with special needs generate heightened concern, stress and tension within their families. Parents of children with developmental disorders encounter a variety of severe hardships in caring for their children's needs and coping with the challenge. Research by Dr. Tali Heiman, of the Department of Education and Psychology, sheds light on the nature of their personal hardship and explores the coping mechanisms parents call upon to deal with their children's everyday functioning. The majority of parents, despite their initial perception of a personal tragedy, expressed a strong belief in the child and in his or her future, an optimistic outlook and a realistic view and acceptance of the disability. The study highlighted the importance of social resources, support services used by parents, the need for effective intervention programs and the support of family and friends, all of which contribute to their resilience, their ability to "bounce back" and cope effectively, despite the considerable adversities.

The objective of this research is to examine family resilience and those factors which help parents to manage in these daunting circumstances. The concept of resilience in the context of family life indicates the ability to cope effectively with challenges and hardships, to function in crisis situations and to demonstrate resourcefulness, as well as the ability to adjust to new and changing situations and to resume constructive functioning.

How Parents Feel

The study focused on parents of children with disabilities in three categories, retardation, physical handicaps or severe learning disabilities. A picture of the tragedy

involved is conveyed by the common responses of parents. 84.4% of the parents in all categories reported having severe emotional responses, such as depression, anger, shock, denial, fear, guilt, sorrow, grief, despair, hostility or emotional breakdown. 31.3% reported negative physiological responses such as crying, not eating, cold sweat, trembling, physical pain, rapid heart beat and breakdown. One parent of a four-year-old girl with Down's syndrome explained: "I felt as if the whole world had fallen on me. I didn't understand how this could be happening to me."

Most parents who talked to spouses, family members or friends received supportive reactions (53%), while 28%



faced a negative reaction, some as extreme as, "Me? I'd kill myself." 81% of the parents cited never-ending emotional and/or physical fatigue, social isolation and the feeling of lack of freedom. 78% cited financial problems. The special expenses entailed usually constitute a heavy burden for the entire family. Private teachers, specific learning courses, consultations, private doctors and therapy constitute major expenses. About half of the parents felt that they lacked accurate information regarding educational settings and services available for their children.

93% of the parents reported that they used psychological services either for the child, for themselves or for siblings.

80% reported referral to educational services, 71% to medical services, and 51% to paramedical services, such as physiotherapy. 55% of parents were concerned about their children's inclusion in society, and especially their financial and physical independence, 50% were concerned about the child's education, finishing school, ability to acquire a profession and have economic independence, and 30% pondered how, in the future, their grown-up children would manage without them, where they would live and what kind of financial and emotional support they would receive.

A noteworthy 75% report that their initial negative reactions and feelings have turned into positive and optimistic feelings of love, joy and acceptance, as well as satisfaction and strength that accompany success in rearing their special child. 28% of parents still felt anger, sorrow, frustration and pain.

Dr. Heiman stresses that while her research reflects the considerable pain and difficulty encountered by parents raising children with disabilities, it would be incorrect to view such families as pathological. It is more correct and beneficial to focus on the strong and positive relationships which parents and families develop and that bolster them.

Three Factors of Support that Help Parents to Cope

The results of the research indicate three sources of support and central factors which favorably affect the parents' ability to cope and to reduce feelings of hardship and stress and contribute to successful functioning:

1. Cooperation, discussion and consultation of parents with family, friends and professionals contribute to strengthening parental functioning;
2. A positive bond between parents which supports and strengthens them;
3. Utilizing the various services

available for diagnosis, treatment, counseling and training, whether assistance is directed to the child or to the family.

Maintaining Optimism and Satisfaction

Despite the various difficulties that parents raising children with special needs indicated, among them health concerns, the financial burden, organizational problems, social difficulties of the child and problems with siblings, 75% of the parents reported a favorable and optimistic outlook and expressed satisfaction with their lives. The expectations of parents that their children will acquire an education and an occupation, will have families and be financially independent are similar to the universal hopes and expectations of parents of children without disabilities. But, alongside their hopes and expectations, one third of the parents dread and fear the day that they will no longer be able to help their children as adults.



It could have been expected that children with different types of disabilities would diversely affect the reaction of parents and the extent of family coping. No foundation was found for this hypothesis. The results of the research indicate that the manner of the family's coping is not significantly different, and the similarity of coping mechanisms was much greater than the differences. It can be assumed that a child with special needs causes disruption of the routine and creates stress, confusion and anger in most of the families, regardless of the precise nature of the disability.

This is preliminary research on the coping of families of children with special needs. In families beset by continuous stress, crisis and hardship, the constructive and favorable mutual support of the family unit, as well as practical support services, promote cooperation and coping, and are the healthy forces that are the key to resilience and successful functioning.

This study demonstrates that it would be advantageous to enhance coping strategies that may contribute to parents' competencies, for the benefit and future welfare of their children, as well as for their own well-being and that of their families.

Symposium: Parents of Children with Special Needs: How They Cope

The Tel Aviv auditorium was packed with over 500 participants in the symposium on "Parents of Children with Special Needs" – all involved in some facet of assisting children with a broad range of disabilities, all seeking an understanding, a formula, academic analysis, some tips, the common mutual support of the large

audience, or whatever might help in their arduous route and never-ending effort to do the best for children with special needs. The foremost researchers, experts and practitioners gathered to share their knowledge and experience in meeting the challenges of crisis, stress and despair and to offer strength and practical tools to adapt to the changing needs of children with disabilities.

Prof. Malka Margalit's research on interaction between parents and the school system offered helpful perspectives on the parents' role. Prof. Haim Omer dazzled the audience by declaring that the approach of many professionals that misbehavior of children with disabilities is the fault of their parents is misguided and counter-productive. Professionals should be trying to strengthen parents in their role

and not undermining or weakening them. Hemda Klein presented a model of professional care for autistic children. Rivka Neeman presented a unique Internet website called "a special place" that offers a wealth of information for parents of children with disabilities. Dr. Iris Manor discussed the importance of a multidisciplinary team in addressing the multi-faceted needs of children with disabilities. The symposium ended with a performance "Allon's Smile" tracing a parent's touching struggle, trials and hopes in raising her disabled child.

A testimony to the importance of this public service was the tremendous response of parents, academic personalities and professionals, flocking to the Land of Israel Museum auditorium to take part in this singular event.

New Course: Attention Deficit Hyperactivity Disorder

ADHD – Attention Deficit Hyperactivity Disorder is a common and widely diagnosed disorder prevalent in at least 12% of school children. The disorder can find expression in a variety of manifestations, among them, difficulties of concentration, sustaining attention and distinguishing between the primary focus and other stimulations. Hyperkinetic, hyperactive and impulsive behavior may also be involved, or combinations of excessive movement and attention disorder. Often misunderstood in the school system, these children are variously referred to as dreamers, immature, lazy, fresh, restless, irresponsible and hostile.

Children with an attention deficit often experience functional difficulties in learning, and in social and emotional interaction at home, at school and with friends. The disorder can extend to adult life, affecting social and family relationships and work. Sometimes the disorder is accompanied by other physical and developmental disorders, sleep disorder, communication disorders and learning disabilities. The course textbook includes information about the role of diagnosis, the medical-neurological perspective, the role of parents, medication, psychological-behavioral aspects of the problem, the family, and treatment. This course is an important service to the many practitioners, educators and family members who seek more comprehensive knowledge on how to teach and raise these children constructively.