

Children and Caregivers: The Role of Resilience

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Much has been done to address the problems of children with special needs and the series of World Congresses on Inclusion of Children with Disabilities has been a critical part of bringing the world's attention to the issues of these children. The results have included greater acceptance of these children by families and communities, and, especially, the provision of the love, support, and opportunities they deserve. However, there are several areas still needing attention, and the world organizations need to focus on remaining needs. These areas include: fathers as caregivers; the stress of caregiving; and adolescents with special needs. In addressing these areas, the role of resilience is introduced

Fathers as Caregivers

It is important to begin by acknowledging the importance of family caregivers, including fathers, who are the ones who assume major responsibility for their children. Once children are removed from institutions, the historical way the children were cared for, family members become the main caregivers for their children with special needs. However, the family member most likely to become the primary caregiver is the mother. But there is sufficient research available now to challenge this practice.

An initial problem with involving fathers in the care of their child with special needs is the old cultural norm that said fathers are authoritarian, detached, providing structure for the family, but not involved in nurturing behavior. By the end of the 20th century, however, it became acceptable for fathers to be more nurturing and to show feelings of caring and empathy.

In many ways, the image of fathers is shaped by economic realities. When men stayed around the home to tend the animals and fields as part of an agricultural society, they were involved with their children on a continuous basis. However, the spread of the industrial society required fathers to leave the home for long days to work in the factories. Their children might be asleep when they left and be asleep when they came home. And now as industry has changed the economic configuration again, with shorter hours, more vacations, leave time, and many fathers working from their home offices, fathers are more available to their children. In some families, the father works out of the home while the mother goes to her job a number of miles away. But, the assumption still exists that mothers are the prime caregivers, especially when children with special needs are involved. This is a great loss for the entire family.

Fathers in the context of family

Barry Carpenter (2002) has brought together powerful evidence of the importance of fathers in the lives of their children. In his article, he point out that the UK government recently set up the new National Family and Parenting Institute and has focused on the importance of the family: "Families are at the heart of our Society and the basis of our future as a country." (Home Office, 1999). But the Institute has had difficulty finding an

accurate and acceptable definition of family and this has implications for services, including those made available to fathers. Current definitions of families are not restricted to blood-relatives, but include significant others, such as neighbors, work colleagues, friends, church members. These others provide practical, moral and emotional support. (B. Carpenter and S.A. Carpenter (1997). Families are defining themselves and R. Winton (1990), in his special report, presents the following definition:

Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. A family is a culture unto itself, with different values and unique ways of realizing its dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Our families create neighborhoods, communities, states and nations. (p.4)

It is fathers, or whoever plays that role, however, who need to receive more attention, as they have so often been neglected by service providers as well as by researchers. Carpenter questions why fathers are not included in the services and why so many of the services are available only at times inconvenient or impossible for them to utilize.

Fathers express concern that the services distance them early in the life of their special child; yet they see themselves as a major resource for the family. The burden, then, is put on the mother virtually alone. But, there is much evidence of fathers not only wanting to be more involved, but, indeed are involved, especially emotionally.

Kyle Pruett (1987), in his studies, recognized the vast changes in the ways men approach the demands of parenting from providers to active contributors to the health and well-being of the family. Fathering is complicated, creative, frustrating, fulfilling, enriching and depleting – all at the same time! And fathers who have children with special needs are challenged every day to balance demands of work with demands of the child, to reconcile their expectations for their child while dealing with the realities of limitations.

Often the stresses that all caregivers experience make some men feel depressed, weak, guilty, powerless, and very angry. Their sense of helplessness and frustration exacerbates the anger. They realize they can't control the condition of the child and can't seem to do anything about it, and that leaves them confused and frustrated. Some fathers simply withdraw from the situation, working longer hours or drinking more.

Other fathers find that their child with special needs opens up new insights about parenting. They feel proud that they can enjoy their child, can nurture the child, and that they can contribute to their child's quality of life.

The Stress of Caregiving

Both parents experience great stress as they adapt to and learn to care for their special child. However, it is clear that women caregivers, the mothers, inevitably are exposed to more experiences causing stress than the fathers. And it is stress that is one target of resilience, that human capacity to face, overcome or even be transformed by experiences of adversity. (Grotberg, 1995). Stress can lead to a variety of undesired

outcomes; depression being a major one. The stress of caregiving is compounded when other responsibilities of women caregivers need attention. They are wives, homemakers, mothers, are often employed outside the home. Some women see these multiple roles adding to their stress while others emphasize the benefits of multiple roles, including relief from one role, achieving in other roles, having a sense of self-esteem with their ability to deal with the adversities associated with the special child, while also achieving in other roles. (Sangeeta Bhatia, 2002) No one role dominated, thus balancing stress with positive feelings.

What emerges from a number of studies, however, is the importance of the perception of the caregivers as to whether or not they were able to deal with the task. When the task was perceived as a problem-solving challenge, mental and physical health remained more intact. To solve problems, the caregiver seeks information and adjusts behavior to integrate the new information. When the task was assessed in terms of how much of a burden the task became, the caregiver remained in better mental and physical health.

Caregivers benefit from having information about what to expect of their special child at any given time as well as over time, so that changes in the care can be made. The sense of control and competence adds to the feelings of optimism and trust in oneself.

Depression occurs when the caregiver feels overwhelmed, alone, blaming herself for not doing better, and feeling the situation is hopeless. The perceived inability of the caregiver to provide the care needed is the most common cause of depression.

Caregivers who verbally express a great deal of negative emotion to their special child find they are more stressed than those who learn more positive communication styles. (S.S. Datta, P.S. Russell & S.C. Gopalakrishna (2002).

And Patricia A. Clark (2002) has provided strong data on the effects of individual and family hardiness on caregiver depression and fatigue. She has defined hardiness as commitment to life, viewing change as challenge, and having control over one's life. And hardiness is related to better outcomes in stressful situations. In her studies, she, indeed, found that hardiness made the difference in whether or not depression and fatigue were evident. The more hardy the caregiver the less depression and fatigue were evident.

M.A. Fallon and T.J. Russo (2003) found in their research that like any other family, military families use family cohesion to adapt to new levels of stress. The authors indicated that these results support the current research literature that families learn over time to adapt to the stress of their lives, sometimes with the aid of services designed to facilitate the process. Clearly, though, some families are at greater risk than others for experiencing extreme stress.

These factors - communication styles, hardiness, family cohesion, and perceived adequacy of social support - all contribute to a family's ability to deal with the stress resulting from having a child with special needs. What is missing is more information on what qualities and behaviors in the special children account for the level of stress they and their families experience. This is an area needing more research.

Adolescents

The Setting

Most of the attention to caregiving and providing services has been for children. Further, the role of families with adolescents having special needs tends to be ignored not only by the services, but also in the literature. And yet, the day-to-day management of the needs of the special adolescent takes place within the context of the family. Further, little attention has been given to the psychosocial impact of the adolescent with special needs on the family.

A. Garwick & H. Millar (1996), of the U.S. Department of Health and Human Services, USA, state: In practical terms, an adolescent with a chronic condition generally receives a disproportionate share of the family resources – parental time, money, and opportunities for compensatory activities. Other members of the family, particularly siblings, often bear the consequences of inadequate family resources (p.7).

Identity

Adolescents with special needs have the same interests as adolescents without special needs. They want above all to be accepted as a person and not as a disability. The self-esteem of young people is more than just a good feeling or a sense of pride; it is the result of being accepted by others, recognized as a good person, respected and loved. Such self-esteem becomes increasingly important as youth move away from receiving major approval from parents to receiving approval from other adults, and, especially from peers. It is difficult for them to see themselves as a good person worthy of

friendship when not accepted by others. The 'special problem' often becomes the focal point of attention and interaction, not the person. The need to 'be like everyone else' is a mantra heard repeatedly from young people.

The need to be like everyone else, however, seems to contradict the need for a sense of identity, and young people face this contradiction continuously. Identity, a clear developmental stage involving the teen years, suggests a need to know who you are, how you compare with others, and what your future might look like. Now, it is most likely the 'how you compare with others' that brings up the need to build an identity that is not defined by the disability. The youth is a competent person, a good friend, has values and high standards, has talents, cares about others. The youth *has* a special problem but *is not* the special problem.

And youth are often resentful of the sympathy because that suggests they cannot function and, indeed, are to be pitied. J. Fleitas (2000) states: Sympathetic responses to childhood illness have the potential to reinforce feelings of inequality and inadequacy, thus placing children in positions of social and personal inferiority. Thirteen year old Kevin complained that "the worse thing of all is to be told that I'm so brave. Kids tell me they could never cope like I do." When others are uncomfortable with what they might see as deviance, blinded to the adolescents themselves yet able to pinpoint their physical differences with precision, the youth acquire a stigma that tarnishes their identity (p.147).

Stigma involves fear. The fear is that the disability of a person is threatening to others, might be contagious, might require providing help or make unwanted demands on

others. There is no way to ignore a disability that is visible, and reactions of stigma are common. Unseen disabilities, on the other hand, often cause rejection of the person because expectations of behavior are not evident. Adolescents need to learn how to deal with the unwanted reactions.

Physical disabilities that are a focus of attention for others are usually not to family members. They become so accustomed to the disability that they forget how others tend to react. It is important, then, for the family to remember and prepare the adolescent for new encounters as the adolescent moves into new settings with new peers. However, some adolescents are known to develop a style of using their disability to control others and make unreasonable on them. Parents and others, out of a sense of caring and sympathy, often become victims of such controlling behavior.

Adolescents are concerned about how they look, their social relationships with peers, their sexuality, their school performance, and their potential for jobs.

The role of the family

It is very easy for families to continue protecting their adolescents with special needs and to prevent them from becoming more confident, more independent, and more connected with friends and groups outside the family. However, the family needs to learn to allow for greater independence of the adolescent, and for other relationships outside the family. These adolescents need more autonomy, and being flexible rather than setting strict boundaries on what the adolescent can do. Those who work with these families are most helpful, however, when they provide the following services:

1. recognizing that the family is the constant in an adolescent's life while service systems and support personnel within those systems fluctuate;
2. facilitating adolescent, family and professional collaboration at all levels of health care;
3. sharing unbiased and complete information among adolescents, families and professionals in a supportive manner;
4. recognizing the strengths and individuality of adolescents and families while respecting different methods of coping and honoring diversity;
5. implementing appropriate policies and programs that are comprehensive in terms of providing emotional and financial support to meet the needs of adolescents and their families;
6. understating and incorporating the developmental needs of adolescents and their families into health care;
7. encouraging and facilitating adolescent-to-adolescent and family-to-family support and networking; and
8. assuring that the design of health care delivery systems is flexible, accessible, and responsive to adolescent and family needs. (p. 10)

But the needs of the adolescent must be balanced with the needs of other family members. For example:

1. identifying and attending to the developmental needs of the adolescent and other family members;
2. encouraging adolescents to discover their own hobbies and interests;
3. encouraging parents to take time for themselves and their relationships;

4. planning treatment regimens with family members so they fit family routines and rituals; and
5. providing services that focus on competencies rather than deficits

Society is devoting much needed time and attention to helping the adolescents and young adults to become working members of society. The Washington Post Magazine, April 18, 2004, a publication of the Washington Post Newspaper, Washington, D.C., U.S.A., devoted the entire issue with stories of a young woman and a young man who received training in jobs and who were excited about their new independence. A young woman became a greeter at a large variety store, and a young man became a maintenance worker at a grocery store. They relish earning money and having greater freedom. The young man lives in a house with other young men having special needs and the young woman lives at home, where she feels more secure.

The Role of Resilience

All of the qualities and characteristics identified as contributing to the well-being of families with a child or adolescent with special needs, are resilience factors.

What is Resilience

Resilience is the human capacity to deal with, overcome, learn from, and even be transformed by the inevitable adversities of life. The research I directed during the 1990s (Grotberg, 2000) involved data gathering in 22 countries at 27 sites. The intent was to determine what resilience factors and behaviors were being promoted and used by families and service providers and children, in dealing with experiences of adversity.

Analyzing some 5,000 responses, it became clear what resilience factors parent and others used not only to promote resilience but to use when facing an adversity of any kind. The resilience factors were organized into External Supports; Inner Strengths; and Interpersonal and Problem-solving Skills. To simplify the concept of resilience, I labeled the sequence as I HAVE; I AM; I CAN. Here is the list:

I HAVE (External Supports)

1. One or more persons within my family I can trust and who love me without reservation
2. One or more persons outside my family I can trust without reservation
3. Limits to my behavior
4. People who encourage me to be independent
5. Good role models
6. Access to health, education, and the social and security services I need
7. A stable family and community

I AM (Inner Strengths)

1. A person most people like
2. Generally calm and good-natured
3. An achiever who plans for the future

4. A person who respects myself and others
5. Empathic and caring of others
6. Responsible for my own behavior and accepting of the consequences
7. A confident, optimistic, hopeful person, with faith

I CAN (Interpersonal and problem-solving skills)

1. Generate new ideas or ways to do things
2. Stay with a task until it is finished
3. See the humor in life and use it to reduce tensions
4. Express thoughts and feelings in communication with others
5. Solve problems in various settings – academic, job-related, personal and social
6. Manage my behavior – feelings, impulses, acting-out
7. Reach out for help when I need it

These resilience factors are used in dynamic interaction and draw from each category. I did not find one resilience response to a situation of adversity that did not involve resilience factors from each category.

Resilience as Process

Resilience is a process involving three major parts:

- a. promoting the factors
- b. engaging in resilience behavior, and
- c. assessing the outcomes

These may be clarified as follows:

- a. The first step in promoting resilience is to promote the resilience factors of I HAVE; I AM; I CAN. Resilience is linked to human growth and development, including age and gender differences. And the resilience factors can only be promoted as a child grows. For example, we cannot expect a two year old to deal with an injury; adults are needed. But we can expect a two year old to get up after falling down and to trust people to help when needed. It is these resilience factors that are used in the next step of the process.
- b. The second step is engaging in resilience behavior. And that behavior involves dynamic interaction of selected resilience factors from I HAVE; I AM; I CAN to deal with the adversity. The steps include a sequence as well as choices:
 - a. identify the adversity. Many times a person or group is not certain what the adversity is and there is need to define what is causing the problems, the risks.
 - i. For children, a limited exposure to the adversity will build resilience behavior rather than a total exposure, which may be overpowering or traumatic. This would be the case in a situation where the child needs assurance that the

family will be able to comfort and protect, but can understand that something bad has happened, and still play with confidence.

- ii. A planned response assumes there is time to plan for dealing with the adversity. This would be the case in needed surgery, changing schools, addressing the problems and needs to the special child.
 - iii. A practiced response involves talking out or acting out what will be done. This would be the case in a fire drill, meeting with someone who has authority to make decisions affecting the person or group, finding the way to school, dealing with bullies, etc.
 - iv. Immediate response requires immediate action. This would be the case in an explosion, an accident, being attacked, requiring immediate medical attention.
- c. The third step involves enjoying resilience outcomes. The intent is to help individuals and groups not only deal with adversities, but to benefit from the experiences. Here are some of those benefits:
- i. learning from the experience. What was learned and what more needs to be learned? Each experience involves successes and failures. Successes can be used in the next experience with an adversity with greater confidence, and failures can be examined to determine how to correct them. What resilience factors, what resilience behaviors need further attention?

- ii. assessing the impact on others. Resilience behavior should lead to win-win outcomes. In other words, dealing with an adversity is not to be accomplished at the expense of others. That is why one resilience factor is respect – for others and for the self.
- iii. recognizing an increased sense of well-being and improved quality of life. These outcomes are, in fact, mental and emotional health, the goals of resilience.

A final word about the outcomes: Some people are transformed by an experience of adversity. A son is killed by a drunk driver. The mother starts a campaign to have drunk drivers arrested, and succeeds in changing the laws of the country. A man has a debilitating stroke and sets up a foundation to seek funds for conducting research on the problem. A young boy contracts HIV and AIDS and spends his last months comforting others. These transformations usually include greater empathy, altruism, and compassion for others – the greatest benefit of resilience.

Most people already have some of these factors; they just don't have enough or don't know how to use them to deal with adversities. And some people are resilient in one situation and not in another. This difference usually occurs as they are resilient in more familiar, less threatening situations, but are not resilient in new or dramatically different situations, where they feel at a loss of control over what is happening (Grotberg, (2003)19-22).

A Final Word

Resilience is seen as increasingly important to the well-being of children and families where a child or adolescent has special needs. By examining the needs of fathers as caregivers, the stress of caregiving, and adolescents with special needs, the role of resilience can be seen as a critical part of managing the problems inherent in having a family member with special needs.

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