

## **Why Us? How Families Develop Resilience**

*By Joan Patterson, Ph.D. Reprinted with permission, from Children's Health Issues, May 1992, Vol. 1, No. 1. Published by the Institute for Health and Disability, University of Minnesota.*

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Researchers now need to focus on identifying services that will improve the quality of life for children with chronic illness and their families.

Resilience in individuals has been studied. However, little research has been done on what makes families resilient. While researchers are interested in individual psychological health and social health, the health and resilience of the family has attracted little attention.

The diagnosis of illness and care for children with chronic conditions affect the development of the child.

They affect the family and the way the family responds to the child initially; they affect the pattern of response and how the family incorporates the response.

Some families struggle and falter. But many families successfully reorganize and actually become stronger.

It is not unusual to hear stories about how a family was strengthened in the face of disability. Parents and children will tell you how they pulled together and came to feel closer in doing so. In resilient families, this commitment takes the form of active efforts to keep the family unit together, sharing the responsibilities and tasks, and maintaining an optimistic outlook on the situation.

Resilient families learn to balance the special needs of the child with the other needs of the family on several levels.

Decisions made about health-related services, special education needs, and home treatments and therapies need to be integrated with other family priorities and decisions. This balance between child needs and family needs encourages independence in the child with disabilities.

Time, energy, and money are also shared as equally as possible. Families tend to make a better adjustment to disease and disability when they are able to focus on matters other than the disease. The resilient family does not attempt to be a "super family." They are realistic and flexible and accept less than workable solutions.

In resilient families, day-to-day family life incorporates the child's disability needs into the daily doings. Grocery shopping, hockey games, television viewing, and car pooling remain important to the overall functioning of the family.

Resilient families tend to establish priorities based on shared values of family members. They protect their sense of identity by maintaining normal family routines. Within families, two or three members may unite because of shared interests, concerns, or goals. For example, there are the adults the parents. And the kids<sup>3</sup>/<sub>4</sub>brothers and sisters. In some families, the "boys" are a subgroup, the "girls" another. These partnerships, often organized by generation or gender, contribute to optimal family functioning.

However, families experiencing stress, especially chronic stress, can become out of sync. When a child has a chronic illness that requires the nearly constant attention of one parent, the other parent may be excluded or withdraw. The ties that bind this partnership may be threatened.

Decision-making can be undermined. Bonds of affection can collapse.

When the marriage is allowed enough time and is nurtured, through mutual respect and support the family is better able to adapt.

Resilient families also protect themselves from too much outside intrusion. They are able to keep the roles of educators, health caregivers, and others in perspective. They maintain professional relationships with the people who provide service, while maintaining a sense of control over their lives.

***“Parents tend to overprotect the chronically ill child, but independence often improves the child’s psychosocial development.”***

Once a child is diagnosed, communication becomes an issue. Parents and brothers and sisters need to learn how to explain the situation to friends and families. They may need to learn a new language as it relates to the description and understanding of the condition. They may need to learn a whole different communication system.

More important, family members need to learn to express their whole range of emotions, especially as they relate to the child with disabilities. This includes providing the opportunity to express anger about the impact the illness is having on family life, fears about the future, resolving conflicts about roles, and sharing positive feelings of caring and commitment. In the resilient family, expressiveness is associated with better child and family outcomes.

Families need to address the question: “Why me?” They need to define the situation in a way that makes their life easier and provides meaning within the family’s value system. Developing a positive attitude toward their child’s condition helps parents adapt to their situation. Many parents acknowledge the positive contributions that their child with a disability has made to their family’s life. Resilient families find meaning in facing the challenge of adversity.

Families living with disability need to become more flexible than other families. In several studies of childhood disability, better outcomes were found when families used flexibility in setting rules, establishing roles, and defining expectations.

Resilient families actively learn about the disability, find needed services and programs for their child, and balance competing family needs. These efforts contribute to a sense of mastery and allow the family to maintain its integrity and autonomy. They learn interdependence with others, which goes beyond the disability needs and positively affects all aspects of family functioning.

Nonetheless, the presence of a child with disabilities can contribute to a family’s social isolation. Families need to maintain and create social relationships. When families are proactive in maintaining their existing network and in developing new relationships, the chronically ill child, siblings, parents, and the whole family, are better.

### ***Child arrives with a chronic illness***

Finally, professional service providers doctors, therapists, social workers, teachers, and the like are an important part of the life of families when a child has a disability.

The quality of the relationship established with these professionals can have a decided impact on a family’s lifestyle. Responsibility for making this a respectful, collaborative relationship resides with both families and professionals. Taking time to share information, working together to make decisions about the child’s care, respecting differences, avoiding attempts to control the

other, and sharing risks are factors that contribute to satisfaction on both sides. There are many families who show resilience when they learn of their child's disability. They already have, or soon discover, their internal and external capabilities. With these families, health care givers need to be careful not to undermine the family's strength through medical inflexibility. There are probably even more families who have the potential to develop resilient behavior. They manage, but with great difficulty.

These families could benefit from timely education focusing on problem-solving and coping skills, emotional expression, and processing of difficult feelings and discovering sources of support from within, and outside of, the family.

### How Other Families Do It

Life would be a lot easier if the same stress reliever worked for everyone, or if the same stress reliever worked all the time. But no one coping mechanism works for everyone all of the time.

Nevertheless, some choices parents make work better than others to help strengthen relationships and families. Here's what some parents do to help ease the stress of caring for a medically fragile child.

<b>STRESS RELIEVER</b>	<b>% MOMS</b>	<b>% DADS</b>
Take one day at a time	17	13
Have faith in God; pray	9	13
Recognize priorities; make positive attributions	20	13
Stay calm, accepting; don't worry	13	10
Take time to be alone; reflect	24	5
Hobbies, projects, recreation	13	33
Humor	4	0
Rest, exercise, nutrition counseling	13	8
Discuss things with friends, relatives	15	3
Do things as a normal family; build closeness	11	6
Share responsibility with spouse	9	13
Be organized; get more help	9	10
Invest in job/work	11	18
Invest in volunteer groups; advocacy	7	3

You may contact the Institute for Health and Disability at The University of Minnesota, Box 721, Minneapolis MN, 55455.