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Risk and Resilience: Children and Youth with Disabilities

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Resilience...The tendency for a child, adult, or family to rebound from stressful circumstances or events and resume usual activity and success. Resilience is the power of recovery.

Popular wisdom (and much of the research literature over the past 20 years) suggests that children who live with chronic disease or disability are more likely to have psychological and behavioral problems than their non-disabled peers.

However, that just isn't the whole story. Individual factors relating to the condition or disability, the child who is affected, the family, and the community all contribute and diminish risk among the children and youth with chronic conditions.

Chronic Conditions

For the past ten years the Center for Children with Chronic Illness and Disability (C3ID) has maintained, as both a guiding and research principle, that regardless of the condition, children with chronic illness or disability and their families, have more in common than not.

And, while we've learned that a specific diagnosis may not be the primary thing that determines how well a child and family do, certain characteristics of chronic conditions do have differing impacts.

Invisible conditions like diabetes or cystic fibrosis are generally more stressful and are associated with more psychological and emotional problems for children than those that are visible. "I never had any question about it," says one adult with cerebral palsy. "I knew I had a disability every time I passed by a mirror. How I looked affected who I am."

It's not easy for those with less visible or invisible conditions. The child and the family are never quite sure if they should tell others about the condition or if they should restrict certain activities that may exacerbate the condition. Parents with children who have epilepsy struggle: Should we let him drive? Can he play baseball? Should the child with asthma be excused from gym class?

Uncertainty

Uncertainty adds stress to the lives of our children and families. A condition that has an unstable course, such as the remission-recurrence cycle of childhood cancers, is more stressful than a condition that remains constant for a long period of time. Likewise, conditions that are unpredictable -- those where having a seizure is a possibility or level of energy changes from day-to-day -- increase the stress on the child and the family. Uncertainty from a lack of diagnosis or changing prognosis (as in the case of life expectancy in those with cystic fibrosis) has been associated with more psychological problems and greater strain.

According to one physician and researcher, John Rolland, MD, the characteristics of chronic conditions have a greater impact on the family than the diagnosis. The course of an illness (progressive, stable, or uncertain) and varying prognoses (improvement, persistent, fatal) have different effects on different families.

- Uncertainty in the course or the prognosis can be more stressful for families who are goal-oriented and prefer to plan ahead.
- An incapacitating illness with a stable course and normal life expectancy places a particularly long-term burden on the family.
- Mothers who are often the primary caregivers for children with chronic conditions experience more depression the more incapacitated and dependent the child.

Painful, unpredictable, embarrassing or energy-depleting conditions can create risk for emotional problems.

No chronic illness or disability comes with "protective" factors per se. Protective factors, as well as risk factors, are a result of the interaction of the child with the chronic illness in the family and in the community.

The Child

We know that, among all children, those with an easy and more sociable temperament do better. While we have little evidence that different child characteristics (gender, self-esteem, etc.) among those with chronic illness or disability make a difference, we do know that:

- Mental retardation is a risk factor.
- Boys with chronic illness or disability may be more likely to have psychosocial problems.

Understanding the different factors influencing child development is complicated because many child characteristics change over time. For example, the personal characteristic of "self-esteem" may be viewed as a health outcome and as a protective factor that contributes to desired child functioning.

Likewise chronic conditions complicate the accomplishment of developmental tasks. What is considered "cute" or "sociable" in an 8-year old may be considered unacceptable in a 12-year old. Parents may be unsure about what is "normal" for their child and how much autonomy to allow.

The issue of independence takes on new meaning when limitations associated with the condition challenge the expectations of parents and youth. When parents and their teenage children are able to redefine independence as the capacity of individuals to take responsibility for their own behavior, to make their own choices, and to develop supportive adult relationships, adolescence tends to be smoother.

The Family

Chronic conditions present most families with a whole set of extra tasks, responsibilities and worries including:

- Extra care needs for the child
- Finding and accessing medical and educational services
- Paying for services
- Emotional grieving of losses
- Uncertainty about the future
- Social isolation
- Stigmatizing reactions from the community
- Lost work and social relationships

The response of the family can be viewed as a source of added risk associated with poor outcomes or as a source of protection that supports the child and leads to good outcomes.

What makes for a resilient family?

- They realize there is more to life than managing a child's illness or disability. They try to balance the child's demands with activities that provide personal fulfillment and satisfaction.
- They sit down with other family members and discuss how they operate. They have clear boundaries between adults and children. Their roles are clear.
- They spend time listening to one another and develop a vocabulary that everyone understands.
- They infuse their family and family situations with positive meanings. Rituals like popcorn and videos on Friday night or breakfast at McDonalds can be fun for everyone.
- They maintain commitment to the family as a unit. They do things together, share responsibilities and tasks, and maintain an optimistic outlook.
- They learn to define difficulties and then become effective, efficient problem-solvers. They learn to cope.
- They develop strong relationships and social ties.
- They become partners with the physicians, therapists and caregivers.

Resilient families are able to shift gears and change expectations. While flexibility benefits all families, it is particularly valuable when long-term demands are present and when day-to-day life is not predictable.

The Community
When families live in strong communities that have supportive people in the neighborhood, peers, and work associates, families do better. These connections provide:

- Emotional support that allows families to feel liked, cared about, and valued;
- Ideas, resources, facts, advice and helpful hints that contribute to problem-solving and decision-making, and
- Tangible aid like baby-sitting when a family member needs to run an errand.

When families are able to maintain frequent interaction with their social networks, it can help to maintain the parents' and family's sense of esteem and competence.

We are learning, however, that the attitudes and behavior of people in the community are often a greater source of strain than having a child with a chronic illness or disability. In some instances, even the service providers hold negative attitudes and biases about children with disabilities. Sometimes, they are judgmental. When this happens, families often avoid the use of services.

We are also learning from our longitudinal study, Project Resilience, that communities and social structures can present greater risks for children and their families than their chronic illness or disability. We can no longer understand disabilities as inherent "defects" or problems to be solved. Rather, we are learning that the capacity of communities and societies to adapt to the needs of the individual determine the extent of the disability.

For more on the topic of resilience, see Resilience: Can It Be Bottled?, published in the free newsletter *Children's and Youth's Health Issues*.

About The Institute for Health & Disability
The Institute for Health & Disability is a network of programs for children and youth and

their families designed to improve the health and functioning of children and youth within the context of their families and communities. These projects share a focus on young people from birth to 24 years of age, and share the fundamental belief that children with chronic illness or disability share many of the same needs regardless of their medical or health condition. They adhere to the following fundamental beliefs in all of their research, training and dissemination projects:

- The family is the central influence in the lives of children.
- Full community participation by children and youth with disabilities and their families has mutual benefit for the child, family and the community.
- Beliefs and attitudes about children and youth with disabilities shape outcomes; positive beliefs contribute to competence; negative beliefs undermine it.
- Normalizing life experiences foster the development of psychological and social competence.

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