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What Families Need to Thrive

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Editor's note: Thanks to Dr. Van Riper for writing this article for Down Syndrome News.

My program of research concerning families of children with Down syndrome started more than 15 years ago when I began working with Nealy Rothe, a young girl with DS, and her family as part of my graduate studies in nursing at the University of Wisconsin–Milwaukee. Nealy's parents not only shared their own stories of becoming aware of and living with Nealy's diagnosis, they quickly introduced me to the "world of DS."

Within a relatively short time, I was attending DS support group meetings and making presentations at local hospitals with mothers of children with DS. I also conducted my first research study, *Parental responses to the birth of child with DS*. This study's most important finding was that the families I interviewed did not sound like the families of children with DS I had read about in the literature. That is, rather than using words like "burden," "tragedy," and "suffering" to describe their child and the experience of raising a child with DS, these parents used words like "joy," "challenge," and "thriving."

The families I interviewed consistently reported that the positive consequences associated with raising a child with DS far outweighed the negative consequences.

Since completing my first study in 1987, I have had the pleasure of working with and learning from more than 350 families that include a child with DS. To date, I have conducted six different studies about families of children with DS.¹⁻⁹ Some of these studies focused on a specific event, such as becoming aware of the diagnosis. Others focused on family-provider relationships or how parents, siblings and the family as a unit respond to the challenges associated with raising a child with DS.

Currently, I am working with a colleague of mine at the UNC-Chapel Hill School of Nursing, Dr. Suzanne Thoyre, on a study concerning feeding issues for children with DS and their families. I also have an ongoing study concerning the family experience of prenatal screening for DS.

Key Findings

- While the birth of a child with DS may initially be viewed as a tragedy, this interpretation usually changes dramatically over time. For example, one mother said,

“All of us have learned to look beyond face value. Before our son was born, there were no disabilities in our very large family. I think it at first shook our perfect world, but now in three years our world has broadened. We have all watched something wonderful grow out of what was initially felt as a tragedy.” ^{7 (34-35)}

• Uncertainty is a major characteristic of the life transition experienced following the birth of a child with DS. Initial sources of uncertainty include:

- **The unexpected diagnosis of DS.** Despite increased use of prenatal testing, many parents do not become aware of their child’s diagnosis of DS until after the child’s birth. Most parents enter the birth experience expecting to have a healthy child, not one with health problems and developmental delays. One mother noted, *“When a child is conceived, a dream is born. The dream image [is of] a healthy, strong, and clever child who with confidence and success, fulfills a parent’s desire to bear a child...when we received the news that she had DS, it was as if the child of our dreams had died.”*⁷

- **Parental concern about the child’s future and the family’s future.** For many new parents, becoming aware of their child’s diagnosis of DS and associated health, development, and educational needs is like entering a whole new world — a world filled with health care providers from a wide variety of disciplines, support groups and early intervention programs. It is a very different world than the one they imagined and for which they planned. Some parents report feeling the need to pin down or forecast the future.

- **Apprehensions regarding parenting abilities.** Initially, many new parents feel inadequate or unprepared to care for a child with DS. Early access to support and guidance from professionals with expertise in DS, as well as other parents of children with DS, can play an important role in decreasing apprehensions about raising a child with DS. Unfortunately, not all parents get this. Parents with inadequate support and guidance are more likely to have difficulty dealing with the ongoing challenges associated with raising a child with DS and may experience decreased individual and family well being.

- **Initial responses of health care providers.** The initial responses of health care providers can have a profound impact on parental uncertainty. Parents who are informed of their child’s diagnosis of DS in a caring, sensitive manner by health care providers who have access to up-to-date information about children with DS and their families experience less uncertainty and are in a better position to deal with the ongoing challenges associated with raising a child with DS. Parents who are given

outdated information in a cold, uncaring manner may have difficulty moving forward. According to one father, *“the failure of others to inform us adequately from the start – that fostered a climate of uncertainty.”*⁹ A mother noted, *“They generally ignored me and avoided talking about my daughter. They didn’t realize that what I wanted and needed was someone to say, ‘Now she’s here, it is time to go on,’ they made time stand still. I couldn’t move forward”*.⁷

Ongoing Sources of Uncertainty

- **The child’s educational program involvement.** Many parents report experiencing increased uncertainty when their child with DS changes classes, teachers, and educational programs.
- **Parental concern about the future.** Now that life expectancy for individuals with DS has increased to 55-60 years, there is greater uncertainty regarding who will provide care and support for individuals with DS when they reach adulthood. One approach that has helped to decrease parental concern about the future is devoting certain support group meetings or conference sessions to a discussion of how best to meet the needs of adults with DS. It also may be helpful for parents of young children with DS to talk with parents of young adults with DS. However, due to all the changes that have been made in the care, education, and treatment of individuals with DS, adults with DS today, may be very different from adults with DS 10 to 20 years from now.
- **The child’s health status.** For many parents of children with DS, the child’s health status is a major source of uncertainty, especially during the child’s first year of life. Using the *DS Health Care Guidelines* (available at <http://www.denison.edu/collaborations/dsg/health99.html>) helps to decrease uncertainty associated with the child’s health status because the guidelines identify health concerns commonly seen in individuals with DS and they provide parents and health care professionals with a roadmap to follow in terms of recommended evaluations and treatments.

More Key Findings

- Families of children with DS generally experience higher levels of stress than families with typically developing children because families of children with DS are subject to the challenges faced by families of typically developing children, plus the additional challenges associated with raising a child with DS (increased caregiving difficulties, changes in roles, and increased time demands).⁴⁻⁵

- While some families find it difficult to adapt to the ongoing challenges associated with parenting a child with DS, other families are resilient and thrive. The availability of individual, family, and community resources plays an important role in how families adapt to the ongoing challenges associated with raising a child with a chronic condition. In communities with limited resources, families end up spending a great deal of their time looking for and/or creating their own resources. In addition to being time-consuming, this may lead to a decrease in individual and family well being. So unfortunately, at present, geography or where you live does seem to matter. Currently there is a need to help more families gain access to available services and resources. There are some wonderful online resources concerning children with DS and their families, but these resources only can be helpful to families if they can access them.

- On measures of individual, marital, and family functioning, families of children with DS are more comparable to, than different from families of typically developing children.⁸

- Parents of children with DS who have positive, family-centered relationships with health care providers report greater satisfaction with care, as well as higher levels of psychological well-being and family functioning.⁴

- Both parents and siblings of children with DS report that their lives have been profoundly influenced by the experience of living in a family that includes a child with DS. More importantly, they report that the positive consequences of this experience far outweigh the negative consequences. Positive consequences included: bringing the family closer together, learning the true meaning of unconditional love, putting things in proper perspective, and appreciating diversity.^{5,7,9} According to one parent, *“Our entire family and marriage is stronger. It has changed our view of the world, our view of others and us. It has made us more giving and less selfish. It has drawn us closer to God. It has caused us to be more concerned about others who are different. It has shown us what we value in life — relationships — not power and wealth. It has made us more content to just be!”*⁵

Siblings of children with DS wrote the following. *“My brother has taught me more than he will ever know. He has taught me patience and how to be more accepting of others.”*⁵ And, *“He has been a blessing to our family. We were getting way too comfortable and set in our ways. As soon as he came into our family we had to stretch ourselves. He has taught us the meaning of love and how the product of love can grow and become such a beautiful person.”*⁵

The more I work with and learn from families, the more I believe that the phrase “A Change of Plans” (used in a new parent booklet developed by the parents of children

with DS that I worked with in Milwaukee, WI) captures the family experience of giving birth to and raising a child with DS. Giving birth to and raising a child with DS is not an awful experience or a tragedy: it is a different experience. *Welcome to Holland*, written by the mother of a child with Down syndrome, Emily Perl Kingsley, conveys this more eloquently than I will ever be able to. [Find it at www.ndscenter.org].

How to Thrive and Be Resilient

- Take time to grieve the loss of the child you expected or dreamed about having.
- Make a point to recognize that while each family member has certain limitations or problems, they also have many strengths and these may actually be much more important than the limitations or problems.
- Don't be afraid to ask for help — whether dealing with emotional issues, finding a caring health care provider, or getting your child with DS into an educational program that fits his or her needs. You are not alone. There usually is help available — professionals, other parents, friends, relatives and people in the community. Sometimes, they are just waiting to be asked.
- Focus on helping your child with DS, as well other family members be “the best of whatever they are” — not what they think others think that they should be.

Douglas Malloch's poem, *Be the Best of Whatever You Are*, says this well.

If you can't be a pine on the top of the hill, be a scrub in the valley — But be

The best little scrub by the side of the hill. Be a bush if you can't be a tree.

If you can't be a bush — be a bit of the grass, some highway happier make.

If you can't be a muskie, then just be a bass — but the liveliest bass in the lake.

We can't all be captains; we've got to be crew. There's something for all of us here,

There's big work to do, and there's lesser to do. And the task we must do is the near.

If you can't be a highway, then just be a trail. If you can't be the sun, be a star.

It isn't by size that you win or you fail — Be the best of whatever you are!

If you, or a member of your family, participated in any of my studies, I thank you with all of my heart. You have taught me so much and enriched my life. You also have helped make getting a master's and a Ph.D. an enjoyable experience. Please contact me if you

are interested in learning more about my research. I can be reached at vanriper@email.unc.edu or 1-919-966-5329. Thank you again.

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