

*An article by Alan Shain\**

A newborn child is seen as an addition into the family and is always a cause for celebration. The parents take pride and joy in watching their child take its first steps and say its first words.

But what if the child has a disability? Do families feel any 'less' proud of their child? To most parents of children with disabilities it is absurd to even ask such a question.

"Hannah is Hannah, and I wouldn't trade her in for the world," states Mary-Anne Burke, president of VIEWS Ottawa, in Canada. VIEWS is a parent-support group for families with children who are visually-impaired.

Burke's daughter, Hannah, is blind. "She sees things no one else does. When there's a family argument, she's often the first to pick out the real root of the problem." Hanna is 19 and has just moved away from home to attend University.

Dr. Kate Scorgie, from the University of Alberta, found that parents value their child with disabilities as contributing positively to the family. In 1996 she conducted an in-depth study of almost 100 families of children with disabilities. While the discovery that their child had a disability was "traumatic", most families had adapted quite well to the new challenges that this presented.

"What parents described was really a journey, one in which, often to their own surprise, they discovered themselves transformed," says Scorgie. Her study is thus appropriately entitled 'From Devastation to Transformation: Managing Life when a Child is Disabled.'

These results are in direct contrast to the often held assumption that these children only present hardships and despair. Traditional approaches to families of children with disabilities focus on 'coping' with grief and lost hope. Researchers typically claim that an attachment to the child will not develop because of the disability. Professor Dick Sobsey, also from the University of Alberta, cites a 1991 discussion on the early stages of parenting as claiming that "far from being a source of pride, (the child) has become proof of parental failure."

"This statement tells us a lot more about the attitudes of certain child development specialists, and almost nothing about the attitudes of parents with disabilities," states Sobsey. Positive accounts from parents are often treated as a form of denial.

"The horror is in the professional's position of power and influence," Sobsey contends. "Parents of a newly diagnosed child with disabilities often don't know how to react yet. This makes them particularly vulnerable to getting bad advise."

Families frequently face controversial issues such as withholding life-saving treatment or terminating the pregnancy. Scorgie argues that by catastrophising disability, parents may make decisions that they will later regret.

Far beyond simply managing, Scorgie's study reveals parents having benefited from their child with disabilities. "I've learned how to dream," states one parent of a child with Down's Syndrome. "Not just for him, but for myself. A world has opened up for me. My self-concept has been changed. I went from seeing myself as not having a lot to give the world, to actually discovering a new world. I discovered the passion in me. I discovered what was really there."

These transformations included attaining new life skills, acquiring new perspectives, and establishing new networks within the community. Parents also stated that the family itself was strengthened. Through their child with disabilities, Scorgie found that 92% of parents felt stronger in reaching their personal goals, 85% felt they had learned what is most valuable in life, and 91% felt they had become more compassionate to others.

Parents reported being personally enriched by new roles they have taken on, such as parent group leaders and conference speakers, due to having a child with disabilities. 83% of parents stated that they had advocated for some one else's needs and had affected positive change.

Sobsey brings attention to various vocational changes brought about by the parenting of a child with disabilities. Sheila Hollins, who now heads the Division of Psychiatry of Disability at the University of London, Ontario, was completing her training when her son was born. Her son's disability served to channel her career interests. Hollins has become a major contributor to the field of dual diagnoses. Sobsey also cites how the famed singer, Neil Young, was influenced by the birth of his son, Ben, who had disabilities. It is unlikely that Young would have gotten involved with designing voice synthesizer equipment had it not been for Ben. Ben was inspiration for his 1982 album, *Transformer Man*, in which Young sings about how his life has been changed through his son.

All this is not to deny that parents of children with disabilities have negative experiences. The existence of a disability often places stress and unique demands upon the family. Yet, the question about Hannah being a burden on the family causes Burke to laugh. "The real disability is the handicap that society places upon my child."

The main obstacle that families cited in Scorgie's study was "the system." Parents complain that hospitals, support services, and school systems are largely insensitive and inflexible in accommodating a child with disabilities. "You have to take on these giant systems that are so entrenched and rigid, and it takes so much time. Half your life is spent trying to convince people," one parent stated.

"Everyone specializes in this area and that area, and you have to run from this professional to that professional and no one was looking at my kid as my kid," says Burke when describing her experience shortly after Hannah was diagnosed with a disability.

A few professionals are supportive. Yet, Burke had to travel 350 miles to Toronto to find one. "She was one of the leading octomologists, but the reason she was great was that she took a real interest in Hannah as a person. For two years she phoned to speak to Hannah once a week about how things were going."

For most parents, it is other parents of children with disabilities who offer the best kind of support. This type of networking enables parents to discover ways of dealing with the restrictions and negative attitudes that they encounter. It also enables parents to be positive when facing these barriers.

One mother told Scorgie, "At the hospital they gave me the name of another woman who had a child with Down's Syndrome. So I called her, and that was a real turning point. She just changed things around, and changed my outlook. I thought, Oh my goodness, there is a positive side to all this. I remember being amazed that she could actually laugh."

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