

*family*

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### Abstract

This article focuses on the belief that persons with disabilities contribute positively to their families, their communities, and society. Traditionally our society has focused on the burdens families face when one of their members has a disability - here we learn a little about the strengthening effects disability has.

**Keyword: Families**

## **DISABILITY AND THE FAMILY: LIFE-STYLE, NOT LIFE-SENTENCE**

"If today I were given the choice to accept the experience, with everything it entails, or to refuse the bitter largesse, I would have to stretch out my hands - because out of it has come, for all of us, an unimagined life." The writer, a parent of a child with a disability, is summarising fifteen years of family experience. (C. Park, *The Siege: The First Eight Years of An Autistic Child With An Epilogue Fifteen Years After*, 1982, Little.) How typical is this attitude? How real?

Is it possible that some or even many families who face the challenge of disability find rewards that balance or outweigh the frustrations? If so, are the benefits real or are these families simply trying to put the best light on their situation?

Traditionally our society has focused on the burdens families face when disability strikes one of their members. The customary view has been to pity or offer help to those who cannot cope, to admire the heroic efforts of those who manage despite their difficulties. The usual outlook has been to hope they survive, but not to expect them to enjoy the process.

Lately some researchers, particularly at The University of Kansas Beach Center, have been looking into the other side of families' experiences with disability. As a first step in this investigation, the KU team examined copies of letters sent to the Department of Health and Human Services by individuals who have disabilities (or by their parents or relatives) to comment on the 1983 proposed regulations concerning the medical treatment of newborns with disabilities. Virtually all the writers supported the legislation, and 35% reinforced their points by describing at least one positive contribution the person with a disability had made to others, including being a source of:

- joy to the family
- learning life's lessons
- love
- blessing or fulfilment
- pride
- strengthening the family.

For example, one parent wrote of her son, "If he served no other purpose than to give me love, then he served that one and if he served no other purpose than to teach me love, he served that one." Another said of her daughter, "She taught us more about love, courage, faith and life than most of us could teach or learn in 100 years."

Reports of satisfactions or "hidden rewards" families find when caring for a member with a disability also appear in books, journal articles, magazines and newsletters.

- Some adult children caring for frail elderly parents say that they develop a more intimate and rewarding relationship with their parents while discovering new strengths and abilities in themselves. In one study 88% of 89 family caregivers of elderly stroke patients said they would undertake the task again if confronted with similar circumstances.
- Investigations of the well-being of children who have a sister, brother or other family member with a disability living at home reveal such positive outcomes as developing more tolerance and appreciation of their own health.
- Families caring for members who have widely ranging disabilities report that they have grown in patience, humility, compassion, closeness, acceptance, and understanding the true values of life.

But are these benefits real? What scientific evidence do we have for their existence? According to the Beach Center researchers, the reality of the benefits is not the issue, because research shows **it is the way families react to events rather than the events themselves that determines how well families function.**

In fact, many experts maintain that the way we think about events in our lives is the major factor in determining how upset we feel when we face "difficult" situations. Thus, families who see benefits from their experiences are likely to have greater levels of well-being than those who see only problems, regardless of whether the benefits can be proved to exist.

So, while having a family member who has a serious disability is not an experience most people seek out, it can strengthen a family. Certainly it is not desirable to create a new disability label by implying that families who do not see the positives described here are somehow deficient. Rather it can be useful to acknowledge and learn from the many families who accept the reality of a loved one's disability, yet who see that person as a contributing family member.