



## WHAT YOU SHOULD KNOW ABOUT THE IMPACT OF EXCEPTIONALITY ON THE FAMILY

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Having a relative with a disability may have a positive, negative, or neutral effect on family quality of life, depending on individual family characteristics and the type of interactions among family members.

**Affection.** Studies of successful families consistently report the importance of sharing verbal and physical affection and learning about unconditional love. Brothers and sisters of a person with a disability often express feelings of embarrassment, guilt, loneliness, resentfulness, or increased pressure to achieve, related to their sibling with a disability. But they also report more insight, tolerance, interests, appreciation, and other rewards because of their experience with disability. Sometimes the affection family members feel towards the child with a disability is not apparent because of the parents' preoccupation with the child's disability.

**Economics.** Although it is not clear which disability creates greatest costs to the family, several research studies show that families do spend more money on their children with disabilities than on their other children. Extra costs may arise from special diets, transportation, vehicle modification, recreation, adapted clothing, medical care, special services, wheelchairs, architectural modifications, and other needs. Another cost of disability is the reduced opportunity for families to make money because of their child's disability. Often families give up better job opportunities because they don't want to leave their present service system, because they work only part-time; they may change jobs or give up advancing their own educations to care for their children.

**Self-esteem.** Parents may have a drop in self-esteem if they feel that an action of their own or their genetic contribution caused the disability. They also may doubt their parenting skills when their infants don't respond to soothing or stimulation (because of disability effects). On a positive note, self-esteem rises when family members see the connection between their actions for the child and good results. Another influence on self-esteem is the way others - service providers, educators, friends, family members - view the family.

**Daily Care.** In some families, the care needs of the individual with a disability are no different from other family members. However, children with more severe disabilities usually do require more assistance and more supervision of their daily needs. This can take a toll on care givers, especially mothers, who typically take more responsibility for meeting these needs. Research shows that parents, whose children have developmental disabilities and chronic medical conditions, report:

- Approximately 50 percent gave their child extensive assistance with grooming, and medical monitoring
- One-fourth said their child needed to be monitored 24 hours daily
- A little more than half said they had a crisis requiring extraordinary intervention within the last month

Typically, as children grow and develop more self-help skills, parents' care responsibilities often decrease, and children can often assist with more of the household tasks. However, parents whose children have more severe disabilities are often denied the

opportunity to turn over more self-care and household responsibilities to their children. These parents may find themselves having to continue their roles as care givers well into their child's adult years. These can also create stress and burn out for families whose children have disabilities.

**Socialization.** Social relationships are a key factor in family quality of life and are among the areas that families often have feelings of stress and frustration. In one study regarding families who have children with mental retardation, parents reported that arranging socialization was their greatest concern, second only after planning for residential options. In another study about challenging behavior and students with disabilities, parents made several comments about their desire for their child to experience friendships. To facilitate social relationships parents often look for opportunities, make accommodations to physical environments, "interpret" their child to others, and create a "circle of friends," which is an organized group of children interested in associating with a child who has a disability.

**Recreation.** Some families may increase their recreation time; for example, the family who has a child with learning disabilities may become active in swimming to give their child

an activity in which to excel. Other families may have little recreation opportunities because of unavailable community resources, negative reaction to the child with a disability, and lack of accommodation for the child. Some families may become active in "special population" recreating activities, while other families look for more inclusive programs and opportunities.

**Education.** Parents who have children with disabilities often feel they must help teach their children, make sure their children get services, and work toward their children's inclusion into the school and community. This extra effort needs balance to avoid the "fix-it" approach, where well-meaning friends, family, and teachers focus almost exclusively on fixing the child's disability, instead of seeing the child's full range of strengths and needs. Continual "fixing" can ultimately create feelings of inadequacy in the child, and in his or her family, resulting in strained family relationships.

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