

Deaf-Blind Perspectives

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Supporting Families: Training Family Support Specialists

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A family's world often turns upside down on the day their child is diagnosed with deaf-blindness. One mother likened the experience to riding the "Scrambler" at a carnival. Just like the physical gyrations of the ride, her mind spun round and round in dizzying circles as she was emotionally pitched from side to side. When she reached a stable center for a fleeting moment, she was immediately flung so far in the opposite direction that she feared she would let loose and fly off into space. The spinning did eventually stop, and she regained her equilibrium. She credits her family, friends, and the state deaf-blind project family specialist with helping her to steady herself and take her first steps in this new life.

Over the past thirty years, the support movement for families of children with disabilities has developed at a rapid pace. Monumental efforts by parents have been the primary impetus. In the early 1970s the first parent-to-parent groups were established, and in the mid-1970s the federal government funded the first parent information centers (Parent Information Center, 2002). In 1994 and again in 2000 Congress enacted the Families of Children with Disabilities Support Act. The first finding in the act states, "It is in the best interest of our Nation to preserve, strengthen, and maintain the family" (Public Law 106-402).

Families are the most likely constant presence in the life of a child with a disability. As a child grows older, the concerns and needs of the family often multiply, creating an ever-growing need for support of the entire family. When the child is an infant, the primary concerns may be related to medical or financial issues. By the time the child is a young adult, the family must consider these, as well as issues related to employment, living arrangements, education, technology, self-advocacy, and conservatorship. An 18-year study of early intervention programs found that if we expect to have an impact on the lives of children, we must offer comprehensive supports for families (Reynolds, Temple, Robertson, & Mann, 2001). The needs of a child are inextricably tied to the needs of the family.

In response to this increased focus on family support, the United States has seen an upward trend toward hiring parent, family, or consumer representatives to assist in designing and delivering support services for specific populations of individuals with disabilities. Indeed, many funding sources now require this representation. There are multiple benefits to this, a few of which are:

- ◆ Families often trust one another more than they trust a system.
- ◆ Families are driven by personal experiences and passions.
- ◆ Families serve as a reality check for programs, ensuring that services are planned and delivered in a way that is effective for families and children.

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Siblings: Unusual Concerns ... Unusual Opportunities

Julie and Mark Martindale

It was a Sunday morning, and we were frantically rounding up our four young children at church, when a few words from an acquaintance stopped us in our tracks. It was Christmas time, and all the children were supposed to sing in the school program that evening. Our son, who uses a wheelchair and is DeafBlind, was going to be part of the program with all the other children. As this person looked down at Aaron sitting in his chair, she asked, “Is *he* going to be in the program? *He* can’t sing.” Many emotions



Aaron with his brothers and sisters. Aaron (11) is at the bottom, then clockwise are McKenna (10), Hope (8), Brennan (4), Tyler (12), Jordan (6)

stirred in us immediately—anger and hurt at the insensitivity of this individual and even embarrassment and self-doubt. Maybe we should not have put him in the musical.

It was our son Tyler who answered the woman simply and eloquently as we stood there still stumbling for the words to say. Tyler said with confidence and pride, “My brother can sing. He sings with his eyes.” If some day you meet our son Aaron, you will know what Tyler is talking about—because Aaron does sing with his eyes and he says more with one smile than most of us can say with a thousand words.

But it was Tyler who amazed us the most with his answer. It reflected acceptance, insight, and maturity beyond his years. This was a turning point for us. We know that in all the worrying we had done over our typically developing children, we had lost sight of the benefits that come from having a sibling with special needs. It is not an easy road for siblings, but along the way they learn skills and form attitudes that can help them throughout life. Their experiences are not really that different from ours as parents. They didn’t choose this road for themselves, and through the tough times they learn that life is not to be taken for granted. And with our help, they can emerge as stronger, more sensitive, and self-assured human beings, just like us as parents.

We’ve spent a lot of time worrying about the effects of the extra attention that our special needs children get. How could we possibly explain to a two year old why the physical therapist was coming to play with his baby sister, but not with him? She is “special,” but so is he. Was this going to make him feel insecure? Would he feel too much pressure to be the one to succeed because his siblings wouldn’t be able to do all that he was able to accomplish? Would he grow up resentful or angry?

In the book by Donald J. Meyer et al., *Sibshops: Workshops for Siblings of Children with Special Needs* (Paul H. Brookes Publishing Co., 1994), the authors list some of the most common concerns that are associated with being a sibling of a child with special needs and also some of the many positive opportunities for growth that siblings have. Here are some examples:

Unusual Concerns	Unusual Opportunities
overidentification	maturity
embarrassment	self-concept & social competence
guilt	insight and tolerance
isolation or loss	loyalty
resentment	vocational opportunities
increased responsibility	pride
pressure to achieve	advocacy skills

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