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ABSTRACT

Views of parents of children, ages 3-37, with disabilities were investigated. Interviews with 51 families addressed a number of questions, including the following: how they learned of their child's disabilities; the best times for the family; reactions of others to their child; what they think their child might not be able to do; and the hardest thing about having a child with disabilities. Based on the responses, which are summarized, it is suggested that no one is ever prepared to have a child with disabilities. It is recommended that teachers treat parents in an individual manner. Family background, socioeconomic resources, and support (or lack of it) within the family and the community can affect the way the child with disabilities is perceived and treated by the family, as well as the way the family feels about itself. Educators need to remember that having a child with disabilities often puts tremendous strain on marriages and on family finances. Educators also should keep these findings in mind before assuming that parents have the time or energy to implement major intervention programs at home. (SW)

Unexpected Findings in Interviews with Parents of Children with Disabilities

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Unexpected Findings in Interviews of Parents of Children with Disabilities

Special educators and other professionals dealing with parents of children with disabilities often make assumptions about these families. Among these assumptions is that nearly all parents deny that their child has a disability (Daniels-Mohring & Lambie, 1993; Turnbull & Turnbull, 1990). Another assumption is that one of the major concerns of parents is planning for the long range future of their child. This presentation will describe the results of 51 interviews with families of exceptional children. The families in this study included several ethnic groups and family living arrangements. Children of these families ranged in age from 3 to 37 years and were representative of nearly all types of disabilities.

As part of their assignment for a course taught by the author, graduate students interviewed parents using a set of specific questions suggested by Heward, Dardig, & Rossett (1979). Among the questions were: how they learned of the child's disabilities; the best time for the family; a time they would never forget; others' reactions to their child; what they think their child might not be able to do; and the hardest thing about having a child with disabilities. Answers to these questions are important because special educators need to be reminded of some of the realities these parents face on a day to day basis.

1. How they learned of their child's disability: Contrary to expectations, of the parents who answered this question nearly half (49%) knew something was wrong with their child before being told so by others. In fact, two mothers reported that they were told that they were being so neurotic about their child's progress that they should take tranquilizers! One mother of a child with a manic-depressive disorder added: "The assumption by the administrators that I was a misguided parent, not that I had an ill child, kept [my child] from getting real help for years."

When medical doctors did tell the parents soon after the child's birth that the child could be expected to have difficulties (31%), the disabilities were very obvious and usually medically-related. The doctor-identified disabilities included Down Syndrome, cerebral palsy, spina bifida, and expected developmental delays for a child with a very low birth weight (1 pound, 10 ounces). Milder, less obvious disabilities (21%) were usually identified by school personnel.

2. The best time for the family: 84% of the parents said doing things together as a family was their most rewarding time. Other responses to this question included cuddling, swimming, one-to-one time, watching MTV, or listening to Christian tapes.

3. A time they will never forget: Unlike the parents in Heward et al.'s (1979) study who most often reported unforgettable and usually public behavior problems, parents in these interviews mentioned some of the things all parents will remember, such as the time their child went swimming for the first time or had the first haircut. More poignantly, parents also said the time they will not forget is when they were able to communicate with their child for the first time using sign language; when the child actually touched the parent's shoulder; and when a five year old lifted his head for the first time. Another stated that she would never forget when the substitute teacher slapped her son for "popping" his lunch bag.

4. Others' reactions: The reaction of uninformed friends and strangers can be obvious in answer to the question, "What do people think your child cannot do?" Ten parents responded that others mistakenly think the child can't communicate with others; four responded that others think the child is unable to feel or express emotions; and two parents answered that others think their child is unable to behave. In addition, four parents said their child's appearance was deceptive and that others believe the child can do more than the child is actually able to do.

5. What the parent thinks the child with disabilities might never be able to do: Among the responses were that the child might never walk; reason well; stay out of other people's things; "tell me he loves me". Ten percent said that they feared their child would never be able to get married; another 10%, that their child would never be able to talk. 20% of the respondents answered that they thought their child would never be independent.

6. Hardest thing about having a child with disabilities: Some of the responses to this question were heart-wrenching:

- One mother said, "When my son was labeled LD, I felt like I had failed as a mother. I also felt like God had punished me for marrying my cousin. When I told [the grandparents] about our second child with a disability, they really blamed us....They think it is our fault and maybe it is."
- A father commented that the hardest thing was "The stress between wife and I; we argue constantly."

- A parent commented that she would feel embarrassed if people knew how difficult it was to live with and care for her son.
- Two parents stated the hardest thing was lifting their child.
- Another mother, who is herself hearing impaired, said the hardest thing was the decision to place her profoundly retarded and severely physically handicapped son in an institution. The decision was made because of physical and emotional stress; her marriage was also falling apart. In addition, she had to have back surgery because of the strain of lifting her son.
- Another family commented on the financial hardship a child with disabilities placed on their family.

The majority of responses to this question can be grouped into four major categories: thinking of the future, time management, making decisions, and others' reactions. Typical responses for each of these general categories are summarized below.

☐ "I'm thinking what will happen when I'm gone" (8 similar responses). "I'm concerned for his future and worried about gangs and drugs." "I'm concerned about my son becoming a teenager since he's already been picked up for shoplifting." Another mother worried about unforeseen problems, about sickness or how her son will get along socially. A father said he realized that a large part of his time and finances must go to the child with disabilities. Two parents worried about burdening a sibling with the care of the child with disabilities after the parents' death. One parent said, "Other parents look forward to their children some day leaving the nest; my child will never leave the nest."

☐ Four parents said the hardest thing was simple exhaustion and trying to balance their time and energy between the child with disabilities and their necessary household chores. (For example, one mother has to get up at 12:30 AM every day to give her child the necessary seizure medication.) Three parents worried about dividing time among all family members; two parents commented that other family members feel neglected and resentful when so much attention is placed on the child with disabilities. Several mothers who work full time felt guilty about not spending more time with their child or with their husband. One couple was unsure if all the hours they were spending on physical therapy would really help. Two parents commented in almost the same words: "My child wants constant, undivided attention and sometimes I just don't have the energy." As one parent commented: "The care is so constant. Things that others take for granted, like taking a walk, reading a book, or just spending time with each other quietly is not possible for us."

☐ Parents also wondered if they were making the right decisions regarding schooling, therapy, and physicians. They worried about not understanding how best they could help their child. Two fretted about not having enough patience and one father remarked, "I always wonder if there's more I could do to help her; the constant soul-searching of ways to help is never ending."

☐ There were more comments regarding the pain of other's reactions to the family of the child with disabilities than there were comments in the other areas. Parents said the hardest thing about having a child was others' thinking that something the parent did caused the problem. Most upsetting for several was other people's reactions to the child (one father started crying while answering this question), especially in watching their children being rejected by others. For other families the hardest thing was trying to explain the disability to others, including other children. One parent mentioned that people don't give the child with disabilities a chance; it is as though the label has taken away his credibility, Similarly, another parent commented on the dramatic drop in esteem that siblings had for child after he was diagnosed as LD, as can be seen in comments like "Hey dummy, come here" or "Don't explain it to him, he won't understand". The following quotation seems to sum up the feeling of many parents:

"You feel isolated in society because exceptional children are not the norm. So, your average neighbor, friend, co–worker or fellow church goer is not going to be able to understand or share with you life experiences."

Support systems: Knowing the importance of the family's support system in adjusting to the demands of a child with disabilities, parents were asked if they had support from family members, friends, or the community. As expected, there was a variety of responses. Some parents have extended families that were "100% supportive on both sides", including one set of grandparents who moved from Illinois to Texas to be able to help. Other parents said their families provided some support "but a lot of 'I told you so's'." Sometimes one side of the family would be supportive, but not the other side of the family. One parent said she received no support but hasn't asked the family for help either because "they should know without my asking." Several parents commented that their families were hundreds of miles away, and their social life was very limited because of their child's problems and the difficulty in finding baby sitters.

Parents of children with clear-cut medical types of problems (cancer, cystic fibrosis, spina bifida) were more likely to have the support of other family members than were parents of children with mental retardation or learning disabilities or especially parents of children with Attention Deficit Hyperactivity Disorders.

Surprisingly, five families mentioned that the father was more involved with the child with disabilities than was the mother. In regards to living arrangements, one child with disabilities had been adopted; nine lived with a single parent, the mother; one lived with his custodial grandparents; and one child with severe physical and mental disabilities lived in an institution.

Implications for teacher education: Teachers need to be reminded that <u>no one</u> is ever prepared to have a child with disabilities. Like their children, parents must be treated in an individual manner. Family background, socioeconomic resources, support (or lack of it) within the family and the community all can affect the way the child with handicaps is perceived and treated by the family, and the way the family feels about itself. Educators also need to remember that having a child with disabilities often puts tremendous strain on marriages and on family finances.

Educators also should keep these findings in mind before assuming that parents are going to have the time or energy to implement major intervention programs at home. Many teachers and administrators are simply unaware of the stresses and strains many of these families have experienced around the birth and care of their child with disabilities

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