

Perspectives of Parents Whose Children Have Dual Sensory Impairments

Michael F. Giangreco, Chigee J. Cloninger, Patricia H. Mueller, Susan Yuan, and Susan Ashworth
University of Vermont

Although educators and other professionals acknowledge the importance of involving parents in their children's education, few researchers have investigated parental perceptions of educational and related services. This qualitative study identified four major themes during interviews with 28 families whose children have dual sensory impairments. These concerns clustered around parental perceptions of a "good life" for their children, as well as their experiences with fear, frustration, and change. Implications from the analysis may assist teachers, related service professionals, and administrators working with families to understand more fully parental perspectives.

DESCRIPTORS: dual sensory impairment, families, parent-professional relations, parents, qualitative research, quality of life, rural services, special education

Professional educators readily acknowledge the importance of family involvement in the education of children with special needs (Benson & Turnbull, 1986; Carney, 1987; Lipsky, 1989; Turnbull & Turnbull, 1990). Far too often, however, educators pass judgment on the quality of that involvement with little or no knowledge of family circumstances. Educators may concern themselves with issues such as lack of skill generalization from school to home, but seldom inquire into the demands, expectations, or priorities of the family (Featherstone, 1980). Systems change is promoted to accommodate evolving exemplary practices with all the best intentions for students, yet parents are not asked what impact these changes may have on their lives, nor how they define "quality of life" for themselves and their children (Hill, Rotegard, & Bruininks, 1984; Schalock, 1990).

Recognizing the importance of understanding family

perspectives within the educational arena, this study explored the experiences and opinions of families of children with limited vision and hearing (dual sensory impairments), many of whom had other significant cognitive, orthopedic, and medically related disabilities (Vadasy & Fewell, 1986). To date, relatively little educational research has been conducted regarding children and youth with dual sensory impairments (DSI), or more specifically, their parents' perceptions of educational and related services (Baldwin & Bullis, 1988).

Due to the low incidence and multiple nature of their disabilities, students with dual sensory impairments pose unique challenges to the educational system in terms of (a) curriculum, (b) instruction, (c) receiving education within general education schools/classrooms, (d) planning for meaningful transitions, and (e) post-school opportunities (Covert & Carr, 1988; Ellis, 1986; Goetz, Guess, & Stremel-Campbell, 1987; Helmstetter, Murphy-Herd, Roberts, & Guess, 1984). The impact of the limitations of our collective knowledge of this group of students has resulted in the development of curricula that do not match family-focused outcomes, unduly restrictive educational placements, and the development of educational programs that limit options and do not promote a higher quality of life after graduation (Bullis & Otos, 1988; Covert & Carr, 1988; Meyer & Eichinger, 1987). Clearly, significant gaps exist in the research regarding appropriate service delivery practices for students with dual sensory impairments. The impact of these practices on the family unit is yet to be understood fully.

Frequently, parents, brothers, and sisters are the only persons providing continuity throughout the student's entire school career (Benson & Turnbull, 1986; Powell & Ogle, 1985). Thus, it becomes crucial for the family to participate in the design and implementation of a child's educational program (Turnbull & Turnbull, 1990). Given the number and variety of professionals involved in the education of students with dual sensory impairments and the complexity of student needs, families of these children may face intense pressures. Understanding these pressures may shed light on similar areas of concern for a much broader spectrum of families whose children have special needs as well as for the professionals who serve them. Therefore, the purpose

Partial support for the preparation of this manuscript was provided by the United States Office of Education, Office of Special Education and Rehabilitative Services, Demonstration Projects for Deaf-Blind Children and Youth (#H086H80017) awarded to the Center for Developmental Disabilities at the University of Vermont. The content of this article reflects the ideas and positions of the authors and do not necessarily reflect the ideas or positions of the U.S. Department of Education; therefore, no official endorsement should be inferred.

of this research was not only to listen intently and record as faithfully as possible what these families said, but to capture their meaning. This information can affect how teachers, related service professionals, and administrators who work with families whose children have dual sensory and multiple impairments will operate in the future. As the services mandated by P. L. 99-457 are implemented, professionals will be expected to use a family-centered approach to identify and respond to the strengths and concerns of families in meeting the needs of their children. (Bailey, Winton, Rouse & Turnbull, 1990; McGonigel & Garland, 1988). This study is an effort to move in that direction.

Methods

The nature of the questions posed by this study prompted the selection of semistructured interviews as the method of research. The descriptive and inductive approach inherent in qualitative methods determined the study design. The primary objective was to understand better parental perspectives regarding the impact of educational and related services on the lives of children with dual sensory impairments. The research design was based on the conceptual underpinnings of established qualitative methods and techniques (Bogdan & Biklen, 1982; Patton, 1980; Taylor & Bogdan, 1984).

Study Participants

From December 1988 through June 1989, 35 students were listed on the *Vermont Report of Students with Dual Sensory Impairments (DSI)* (analogous to the Federal Deaf-Blind Registry). The Vermont Department of Education defines a student with dual sensory impairments as one who "... is visually impaired and who is hearing impaired in accordance with Vermont regulations, and cannot be accommodated in special education programs solely for the child with hearing impairments or the child with visual impairments, without adaptations designed for these dual sensory impairments". Students are also included in the State Report if they are considered to be at risk for dual sensory impairments. A student is at risk for dual sensory impairments "... when there are inconsistent or inconclusive responses during clinical hearing and/or vision evaluations, and/or inconsistent responses to auditory and/or visual stimuli in the environment, or the student has a chronic or degenerative health impairment that may potentially result in dual sensory impairments" (Vermont Department of Education, 1987). These definitions do not imply that special education programs are necessarily provided in segregated special education settings. Rather, special education programs and services for students with severe disabilities, including those with dual sensory impairments, are provided in the least restrictive environment. Increasingly, this includes general education classrooms

(*Daniel R. R. v. State Board of Education*, 1989; Lipsky & Gartner, 1989; Stainback, Stainback, & Forest, 1989; Williams et al., 1986).

Parents of 28 students from the State DSI Report agreed to participate in this study. The remaining seven families declined participation or could not be contacted. All families interviewed were Caucasian. Twenty of the children lived with both of their biological parents: one lived with his biological mother, and two lived with their grandparents. Of the remaining five children, three lived in two-parent adoptive families. Two children lived in single-parent families, one with a foster mother and another with an adoptive mother. Family size ranged from three to eight with the average being 4.7. Consistent with Vermont's rural nature, 17 of the families lived in towns with populations under 1,000. Five families lived in communities with populations ranging from 1,000 to 5,000, and five resided in communities of 5,000 to 15,000. Only one family lived in a small city of approximately 38,000.

As indicated in Table 1, twenty-six mothers, three fathers, and two grandmothers (who were guardians) were interviewed. Students ranged in age from 3 to 20 years with the majority ($n = 20$) being under 10 years of age. Seventeen of the students were females; 11 were males. Thirteen students received their education in special classes, eight in general education classes, six in home-based programs, and one in a residential school.

As a group, these youngsters had significant cognitive and physical impairments. The labels of mild, moderate, severe, or profound retardation used in Table 1 are an indication of their level of functioning and are not meant to offer a measure of ability. In nearly all cases, it was difficult to differentiate which disability or combination led to the student's level of functioning.

Data Collection Method

The research team met to discuss the purposes of the research, the study design, and a list of potential questions for data collection. The appropriateness of the questions from the parental perspective was addressed by the member of the research team who was a parent of a child with severe disabilities. The team agreed upon a set of questions to ensure that each interviewer inquired about the same issues (see Table 2). The research team agreed that questions were not to be presented to families in standardized ways, or necessarily in the same order. Rather, each team member would individualize his or her question-asking style to match the individual interviews and would follow various paths of questioning based on parental responses.

Parents were contacted by telephone and asked if they were willing to be interviewed. Those who agreed to participate were given the option of being interviewed face-to-face or by phone. Twenty-three parents were interviewed face-to-face; 19 of these interviews were conducted in parents' homes, and the remainder in

Table 1
Summary of Information Regarding Families, 1988-1989

| | Student Initials (Pseudonym) | Sex | Student Age | Person(s) interviewed | Number of interviews | Interviewer | Educational Placement | Student Characteristics (DSI = Dual Sensory Impairment) |
|----|------------------------------|-----|-------------|-----------------------|----------------------|-----------------|-------------------------------------|--|
| 1 | JT | M | 3 | Mother | 1 | PM | Early education (Special education) | DSI. Severe retardation. Severe orthopedic disability |
| 2 | SK | M | 3 | Mother and Father | 1 | SA | Early education (Integrated) | DSI. Severe retardation |
| 3 | AR | F | 3 | Mother | 2 | SY | Early education (Home-based) | DSI. hydrocephalus. Health impaired |
| 4 | KK | F | 4 | Mother | 1 | MG ^a | Early education (Home-based) | DSI. Moderate retardation. Marshall-Smith Syndrome |
| 5 | JB | M | 4 | Mother | 1 | PM | Early education (Special education) | DSI. Moderate retardation. Sturge-Weber Syndrome |
| 6 | JL | M | 4 | Mother | 1 | MG | Early education (Special education) | DSI. Severe retardation |
| 7 | ED | F | 4 | Mother | 1 | PM | Early education (Home-based) | DSI. Within normal range of intelligence |
| 8 | CF | F | 5 | Mother | 1 | SY | Early education (Home-based) | DSI. Profound retardation. Severe orthopedic disability |
| 9 | JY | F | 5 | Grandmother | 2 | CC | Early education (Integrated) | DSI. Severe retardation |
| 10 | JA | M | 6 | Grandmother | 2 | SA | Kindergarten (Regular) | Severe orthopedic disability |
| 11 | KH | F | 7 | Mother | 1 | MG ^a | Special Class | DSI. Severe retardation. Severe orthopedic disability |
| 12 | BV | M | 7 | Mother | 1 | MG | Grade 1 (Regular) | DSI. Profound retardation. Severe orthopedic disability |
| 13 | AT | F | 7 | Mother | 1 | SY | Grade 2 (Regular) | DSI. Down Syndrome |
| 14 | AE | M | 7 | Mother | 1 | CC | Grade 2 (Regular) | DSI. Profound retardation. Severe orthopedic disability |
| 15 | SW | M | 7 | Mother and Father | 2 | PM | Grade 2 (Regular) | DSI. Severe retardation. Severe orthopedic disability |
| 16 | CT | M | 7 | Mother | 2 | MG | Grade 2 (Regular) | DSI. Profound retardation. Severe orthopedic disability |
| 17 | SB | M | 8 | Mother | 2 | MG | Special Class | DSI. Profound retardation. Severe orthopedic disability |
| 18 | JH | F | 8 | Mother | 1 | MG | Residential School | DSI. Mild retardation. Attention deficit disorder |
| 19 | RH | F | 8 | Mother | 1 | MG | Special Class | DSI. Profound retardation. Severe orthopedic disability |
| 20 | LM | F | 9 | Mother and Father | 1 | SY | Home-based | DSI. Profound retardation. Severe orthopedic disability. Medically fragile |
| 21 | DG | F | 9 | Mother | 1 | PM | Grade 3 (Regular) | DSI. Severe retardation. Severe orthopedic disability |
| 22 | LG | M | 11 | Mother | 1 | MG | Special Class | DSI. Mild retardation |
| 23 | HP | F | 11 | Mother | 1 | MG | Special Class | DSI. Profound retardation. Severe orthopedic disability |
| 24 | HP | F | 13 | Mother | 1 | SY | Special Class | DSI. Severe retardation. General motor delays |
| 25 | BJ | F | 13 | Mother | 1 | MG | Special Class | DSI. Profound retardation. Severe orthopedic disability |
| 26 | ED | F | 15 | Mother | 1 | MG | Special Class | DSI. Profound retardation. Severe orthopedic disability |
| 27 | PJ | F | 15 | Mother | 1 | SA | Special Class | DSI. Profound retardation. Severe orthopedic disability |
| 28 | DJ | F | 17 | Mother | 2 | MG | Special Class | DSI. Profound retardation. Severe orthopedic disability |
| 29 | MF | F | 20 | Mother | 1 | MG ^a | Special Class | DSI. Profound retardation. Severe orthopedic disability |
| 30 | MF | F | 20 | Mother | 1 | SA | Home-based | DSI. Profound retardation. Severe orthopedic disability |

^a Member check.

Table 2
Issues Addressed in the Interview Questions

1. Can you tell me about your child's educational history? When did s/he start school? What kinds of classes was s/he in and what other kinds of services did s/he receive? How have services been provided (e.g., directly, consultation)?
2. How much involvement does your child have with nonhandicapped students during school and after school hours? How do you feel about this involvement? Have you always felt the same way about this involvement or have your opinions changed over time?
3. What is it about your child's current educational placement that you like the best and think is most important? What, if anything, about your child's current educational placement would you change to make it better?
4. What do you think are the most important things your child should learn while in school and why are these things important? What do you hope will be the outcome of your child's education?
5. What do you think would happen to your child if s/he was placed in an educational situation that was very different from what it is currently (e.g., if she is now in a self-contained special class what would happen if she was placed in a regular class)?
6. How far in advance do you think about planning for your child's life? Next week? Next year? Adulthood? How do you feel about long-range planning?
7. When your child completes his/her eligibility for public school services, what would a high quality life consist of? What kinds of settings would you like to see for your child and what kinds of activities?
8. How have nonhandicapped children and parents of nonhandicapped children responded to the presence of your child in the public school (building or classroom)?
9. Can you recall any experiences that you or your child had related to school that were extremely negative?
10. Do you feel that you are considered as a full member of the educational team? Do you have an equal voice in decision-making (e.g., selection of IEP goals)? Has this always been the case?
11. How do you feel regarding the involvement and coordination of the specialists (e.g., vision specialists, PT, OT) who work with your child?
12. Can you recall one or two experiences that you or your child had related to school that were extremely positive?
13. Is there any other information about your child's school experiences that you feel are important in helping professionals better consider the needs of families?

other, mutually agreed upon locations (e.g., restaurant, office). Five parents were interviewed by telephone. The interviews ranged in length from approximately 1 to 2 hr. The five members of the research team were assigned families based primarily on geographic convenience.

Each interview began with a review of the purposes of the research and assurances of confidentiality. The parents were then asked the questions listed in Table 2. Data were recorded during these discussions by writing as many direct quotes as possible and taking notes on the substance of the parent response to each question. At times this resulted in short periods, typically less than a minute, of nonspeaking time between questions. Interviewers attempted to augment direct quotes and capture the essence of the parent response by following a pattern of asking, listening, writing, and asking follow-up questions to verify a shared understanding of the parent's remarks. Abbreviated notetaking was used during the interview to maintain the flow of conversation. The same day of the session, the interviewer expanded on these abbreviated notes. The fieldnotes included descriptive information on the setting, parents' comments and responses to questions, and interviewer comments. Fieldnotes were organized by pairing the questions asked with the parental responses. Any written information that was not data directly from parents, such as interviewer comments or perspectives, was labeled as such and listed under the specific parent response that prompted the interviewer's comment. General interviewer comments were also labeled and included at the end of the fieldnotes. All fieldnotes were

organized in a similar format and typed for review by other members of the research team.

Data Analysis Procedures

Following the initial 28 interviews, fieldnotes were analyzed using a qualitative coding procedure (Bogdan & Biklen, 1982). The narrative data were coded and subsequently organized by similarity of theme into categories. Coding consisted of reviewing the text to identify repeated words, phrases, and ideas. Initially, coding resulted in the identification of over 50 categories of data. The data were repeatedly reorganized in an attempt to understand the meaning of parental responses and to make the categories more manageable in size and content. The second major recategorization consolidated the data into 20 categories.

Benefits of group data analysis were apparent as the process went forward. The first round of coding resulted in categorization that was far different from the categories ultimately presented in this article. Initial categories such as "educational placement," "integration," "service delivery," and "curriculum" were educationally driven and did not represent the parental perspective adequately. Recategorization with research team members led to new and different categories that more accurately reflected the ways parents thought about the issues. This interpretation was further studied by team members to determine whether the analysis matched their understanding of the data, based on their personal field experiences. Supporting data were identified in the fieldnotes and a search was conducted for any data that were contrary to the tentative categorizations.

Member Checks

Once the research team reached agreement on coding categories and the subsequent analysis, member checks (Ferguson, Ferguson, & Jones, 1988; Lincoln & Guba, 1985) were conducted with 6 of the 28 families to reduce the possibility that the professional perspectives of the research team might overshadow parental views. These follow-up interviews were crucial for achieving the intended purpose of the research, because internal reliability among research team members is of limited value if the team's analysis does not reflect accurately the meaning of those being interviewed. To minimize bias, therefore, member checks are necessary for establishing agreement on the interpretation of the data between researchers and those being interviewed.

Three families whose children attended special classes and three whose children attended regular classes were selected for member check interviews. Parents who expressed divergent opinions and perspectives during the initial interviews were purposely chosen. During these follow-up telephone calls, which lasted approximately 45 min to 1 hr, participants were presented with the team's analysis and asked to indicate (a) whether the team's analysis matched their own experiences, (b) whether the team's analysis adequately represented a parental rather than professional viewpoint, and (c) whether the data "made sense." Additionally, they were asked to offer opinions that might assist the research team in understanding more fully the parental perspective. The six parents who participated in the member checks indicated strong agreement with the analysis. In a number of cases, parents responded to a finding with sudden laughter, because the team's analysis had "hit a nerve." This laughter was always followed by a confirming statement and often by a story supporting or illustrating the point.

Results

Parents interviewed during this study identified four major areas that dominated their thinking about their child's school experience. These four areas include parental perceptions of a "good life" for their child, as well as their experiences with fear, frustration, and change. The results section culminates with a summary of what parents said they wanted from school professionals.

Quality Indicators: "I want my child to have a good life"

The aspirations of parents whose sons and daughters have dual sensory impairments parallel what might be expected from any parent. When asked what would constitute a quality life for their child, parents identified five major characteristics. The need for a safe, comfortable, stable home was paramount. Parents wanted their children to live in a home and clearly sought to avoid congregate care facilities, such as nursing homes, large

group homes, or institutions. It was also vital to establish and maintain a social network of "people who care." Parents wanted their children to be productive with their time by engaging in work that is valued by society as well as meaningful, interesting, image-enhancing, and preferred by the individual. Although work was considered important by some parents, those who viewed employment as an unlikely option for their children focused their attention on some of its non-monetary benefits. "He needs duties, activities, not necessarily to make money, but to make him feel important, something he's good at, to be useful." Based on these attitudes, parents identified a variety of potentially acceptable post-school options, such as competitive or supported employment, volunteering, continued education or training, and leisure activities. Parents also wanted their children to have ongoing access to multiple environments and activities so that their life would be full and interesting. "I can't picture her being home-based; it's not enough." They consistently indicated that having a variety of opportunities, experiences, and settings was a major part of what distinguished an enjoyable life from a boring existence. Lastly, given the medically complicated problems of many children with dual sensory impairments, parents hoped their children could pursue these quality of life indicators in a state of health and comfort. After indicating that her child's "first year of (his) life was filled with excruciating pain," one mother explained that all other indicators of a good life hinge on relative health and comfort.

The development of social networks was identified as a major unmet need. "My first goal is that he'll have a circle of friends, some peer support; it's just as important as skills." Almost all of the respondent families indicated that the interactions of their children were limited to family members or friends of family members. These children had few friends or even acquaintances of their own. Regardless of the status of the child's social network, the most positive and negative school-related experiences of these families pertained to interactions with nonhandicapped people. Parents stated that some people who made up the social network at school questioned the child's worth and treated the child as though he/she were unwanted. "Sometimes when she is in therapy, I feel they treat her more as an object than a child." Another parent recalled, "Other people have always written him off. His preschool teacher told us that he wasn't worth wasting time on in terms of equipment and teaching when her time could be better spent with other kids who could learn better." Conversely, parents reported their most positive experiences had been when their children were included, welcomed, and treated with dignity and worth. Parents described a variety of positive, neutral, and negative interactions between their children and nonhandicapped people. Parents reported that people who inter-

acted with their children in negative or neutral ways tended to be those with limited or superficial interactions, whereas individuals who "take the time to get to know people with disabilities are more positive."

Parents whose children had access to interactions with nonhandicapped peers in school reported that over the years, different nonhandicapped children demonstrated "genuine concern and interest" as well as "exceptional insights into the needs and feelings" of the children with dual sensory impairments. As one mother reported, "This year it was Lance. He would comfort him when he cried; he invited him to his house; he pushed him on the swings and helped him on the slide." Although parents were unable to explain why these particular children seemed to gravitate toward their children, they did share a common belief of perceived benefits from these interactions. Although parents indicated that their children with dual sensory impairments may or may not have gained anything positive from these interactions, they were confident that the nonhandicapped child "got a lot out of it."

As already stated, the aspirations of parents whose children have dual sensory impairments, as well as possible other numerous severe handicaps, closely parallel the hopes of any parent. Home, health, meaningful personal relationships, valued activity, and varied experiences form a hopeful vision for them. In the best circumstances, parents whose children have dual sensory impairments may face formidable obstacles to realizing their vision. In the worst circumstances, the human service systems in place to assist families (e.g., schools) may, by their organizational design, block the paths to the desired outcomes. The next three sections describe school-based family experiences that illustrate potential obstacles from the parent perspective.

Fear: "Everybody's afraid"

Fear of the future led many parents to indicate they were "uncomfortable" and "avoided" long-range planning for their children because "it's too big an unknown." Parents explained that thinking of the future was too painful and that avoiding it, as an act of commission or omission, was a coping mechanism to reduce stress and unnecessary worry about events over which parents perceived they had little or no control. Having a child with a reduced life expectancy contributed to the avoidance of long-range planning. "I don't think about the future; I don't know if she'll be alive." "It's so hard to visualize the future, especially when I don't see older people (alive) with such severe handicaps."

An additional contributing factor in avoiding long-range planning was parental beliefs about their children's futures. Those parents who had a positive vision of their child's future progress seemed willing, in some cases even anxious, to engage in long-range planning. Those with a pessimistic view of their children's future

tended to avoid long-range planning. "My expectations are very limited; I never had high hopes." These pessimistic feelings were exacerbated when parents perceived a never-ending responsibility for child rearing. "With most children at some point it's up to the children, but not with a handicapped child; it's a lifetime project." In avoiding long-range planning, most parents preferred to take a short-range, "wait and see," "leave it open" approach. As one mother said, "If I think too far ahead I get depressed, so I've learned to take it 1 day at a time."

Although parents acknowledged that some of their own behavior was affected by fear, they believed fear also affected the behavior of professionals. For example, parents indicated that itinerant vision and hearing specialists were involved minimally with their children, although these children with dual sensory impairments presumably need such services. The more severe and multiple the handicaps (e.g., physical disability, mental retardation, behavioral disorders), the less likely the vision or hearing support staff were involved. Parents said they believed vision and hearing specialists could be of assistance in supporting the education of their children, but perceived professionals as "afraid to admit when they didn't know something." Parents believed professionals dealt with their own fears of not being experts by either "not working with the child" or "pretending to know the answers when they don't."

Often parents are described as "overprotective," but parents attached that descriptor to professionals, who, they believed, acted out of fear and not knowing what to do. "School is overly worried about little things; he fell over in circle one day; that's no reason to call." "They're afraid of his seizures even though they are under control." "They always want to send him home as sick when it doesn't warrant coming home; they just don't know how to handle him." Some parents indicated they thought the school district was afraid the child would die, and they didn't want it happening in school. As one parent said, "If something is going to happen, it will happen. I won't blame the school." Another parent echoed this sentiment by saying, "We know the risks; we're not going to sue them. I'd rather have my child die in a regular class at 5 years old than at 20 in an institution."

Frustration: "Dealing with schools can be tough"

For parents, one major frustration with school programs serving students with dual sensory impairments is the sheer number of professionals. "I can remember at one time I just wanted them to leave me alone; it seemed so overwhelming." As one mother quipped, "most kids collect stamps; he collects professionals." Despite the fact that many parents perceived the well-meaning parade of professionals as "hectic," "confusing," and an "invasion of privacy," they cushioned their

discontent by saying they had "no objections to lots of people, as long as it helps."

A few parents reported that the multitude of professionals did help, but as one parent stated, being in the process felt like, "... a ping-pong ball because everyone has a different idea about what's right for your child, and we do too." "They don't see him as a whole person, just different disability segments. Everyone likes to segment him. None of the specialists know what to do when a child has more than one disability. It's frustrating." Many parents said such experiences prompted them to view specialists as people who did not have expertise beyond a narrow band of knowledge.

Statements by parents indicated deficiencies in coordination and communication among team members. "They [professionals] ask the same questions; they need to talk to each other." Those families who had a designated case manager or liaison with the school felt more satisfied. "No matter how many people work with Janie, there is only one contact person." Case managers can help "take the hassle off me." This was especially important to families when the staff changed frequently due to moving, pregnancy, illness, transfers, and so forth.

Parents said they viewed themselves as the coordinators of services because they knew the child best and had both the historical perspective and a vested interest in a future vision for the child. Although parents strongly expressed their desire to have input in their child's educational program, many indicated that "the school staff doesn't feel I'm part of the team." "They share information with me," but "they question whether I know what I am saying." Some parents said it was acceptable to be merely informed "as long as the teachers do a good job." More often than not, parents indicated that being informed rather than included resulted in irrelevant educational planning or decisions that did not match the needs of the child or the family. Parents said they sometimes had to be aggressive and that such an approach was unpopular but necessary. "That was a big problem (being excluded by the team); I raised hell and now it's better." Those families who were frustrated by the behaviors of professionals and who decided not to be aggressive often withdrew from the educational process. They reasoned, "I can speak up, but there is nobody to listen"; therefore, "it doesn't matter what I say because they [professionals] are going to do what they want anyway."

Change: "Sometimes change is harder on us than it is on them"

As students with all types of severe and multiple disabilities are increasingly included in regular schools and classes, parents may be confronted with potential changes in their child's educational placement. Parents whose children received special education in self-contained (special) classes were asked how they thought a

change in placement to a general education class would affect their child. They responded with a consistent list of negative outcomes. Parents said if their child were integrated he/she would regress, be neglected or overlooked, be exposed to undesirable behaviors, not receive enough appropriate stimulation, miss his/her classmates, lack needed learning opportunities, and that the change would be disruptive. Interestingly, when parents whose children received special education services in general education classes were asked how they thought a change in placement to a more segregated class would affect their child, they responded with the exact same list of negative effects. When parents were presented with this apparently contradictory finding during member check interviews, they explained that the issue was not so much integration as it was change. "People are comfortable where they are as long as everything is going OK." Parents indicated they didn't want to risk making a change when they perceived the current situation as acceptable.

Regardless of the extent to which the child's placement was segregated or integrated, a parent's level of satisfaction with his/her son's or daughter's educational placement was strongly attributed to teachers and staff who demonstrated a genuine concern for the child by working hard to make the school experience positive and meaningful. Parents whose children received special education services in general education classes identified several major benefits: (a) the opportunity to absorb as much as possible, given the child's unknown learning potential, (b) building ongoing social networks, and (c) developing a positive self-image. Parents whose children received special education in self-contained classes identified major benefits as stability, a protective environment, and individualized attention. Given the perceived security of a placement where the child was "happy and welcomed," few parents liked the idea that educators had "changed the rules of the game mid-stream" from segregated to integrated. Upon reflection, several parents came to the conclusion that they would probably have been more favorably disposed toward educational integration if it initially had been clearly the direction of the school. They indicated that any change to a more integrated setting would most likely be harder on them than on their child; "even good change can be difficult."

Advice from Parents

Parents were clear and consistent in their advice to professionals. First and foremost, parents wanted professionals to listen to them and trust they know the child best. Secondly, parents wanted professionals to treat their family as individual and unique, treat kids with respect and dignity, and "treat them like kids no matter how little you think they understand."

Parents wanted an educational program with stability that avoided shifting the student to different locations

convenient for the school system but disruptive to the child and family. "Based on where you live, most parents know where their child will go to elementary, middle, and high school, but not us: our kid gets moved around to different schools all over the place every year just because he's handicapped." One parent put things in perspective when she said, "Everything about Sam is unstable and uncertain; anything that we find to maintain stability helps us cope."

Parents longed for professionals who would be honest with them and be secure enough to "admit when they don't know something." Lastly, parents wanted to be included in decisions about changes (e.g., integration) that would have a direct impact on their family. To be heard, trusted, treated as individuals, attain some basic level of stability, to expect honesty, and inclusion in important decisions that affect families, were the requests from these parents. They have challenged the professional school community to practice what they preach.

Discussion and Implications

Although the results of this study highlight a number of perspectives shared by parents whose children have dual sensory impairments, the heterogeneity of people who have dual sensory impairments and their life circumstances indicate that caution should be observed when interpreting these data or making generalizations. The following limitations should be considered. Interviews of self-reported perceptions can be strengthened by comparing the findings with participant observations and analysis of pertinent documents. Also, only three fathers were interviewed and all three of those conversations included the children's mothers. Even though the common link among the 28 families in this study was the children's diagnosis of dual sensory impairment, the vast majority were also identified as having significant cognitive and orthopedic disabilities. The multiplicity and severity of the disabilities, not exclusively the vision and hearing impairments, may have affected parental responses. The majority of these families resided in rural areas and included two parents. It is unknown whether responses would be different from single-parent families or those who live in urban areas. Because the majority of parents interviewed had pre-teenage children, it is also not known whether responses would change significantly as families faced the challenges associated with the transition to adulthood during the teenage years.

Future research may clarify whether the responses of parents whose children have severe and multiple disabilities parallel those of other parents whose children are less significantly handicapped or nonhandicapped, thus identifying whether the phenomenon of parent-hood varies in kind or merely degree. Additional research may determine whether responsiveness to the

issues identified in this study affects the level of parental stress or facilitates achieving the quality of life that the parents sought for their children.

Focusing on Quality of Life Indicators

The parameters that parents identified as indicators of a quality life (e.g., home, health, meaningful personal relationships, valued activity, and varied experiences) can be a focal point for services to children. Putting these indicators into practice should include establishing a clear link between what we want for a child and what we do.

Although educators typically place a high emphasis on skill attainment, the parents generally placed minimal emphasis on skill development for their child. If the skills targeted for instruction were both matched to a family-centered vision for the child and clearly linked to one or more quality of life indicators, parents might find the educational planning process more relevant. For example, during IEP preplanning, many educators meet with parents to identify their priorities for the child. Skill inventories are frequently used in which items are organized into categories such as *socialization*, *communication*, *self-care*, *motor*, and *cognition*. Some educators and parents can see clearly the link between these skills and quality of life indicators; others may not. For those who may not, or those for whom the link is unclear, reorganizing and describing skills to show their relationship to quality of life indicators would be helpful. Instead of sections labeled *communication* and *socialization*, these skills might be categorized as those that *facilitate the development of meaningful relationships or social networks* or *provide enhanced access to varied environments and activities*. Even though many skills will overlap more than one quality of life indicator, purposely linking skills to quality of life indicators can establish and maintain a shared focus among team members (Giangreco, Cloninger & Iverson, 1990).

Because parents focused attention on the development of meaningful personal relationships for their children, it is interesting to note that current service delivery models tend to place children with dual sensory impairments in residential schools, special schools, and special classes (Bullis & Otos, 1988; Vadasy & Fewell, 1986). Such placement dramatically reduces the possibility that relationships will develop between children with severe disabilities and their nonhandicapped peers, who may have genuine concern and interest in them as well as exceptional insights into their needs and feelings. If one makes the assumption that such nonhandicapped individuals exist, and the evidence reported by parents suggests that they do, then opportunities for such interactions must occur if social networks are to be established. G. Kishi (personal communication) suggested that these types of relationships could be supported by fully integrated educational placements and the inclu-

sion of people with severe disabilities in a wide variety of typical environments and activities. Such situations provide opportunities for interactions with many people, some of whom may gravitate toward people with disabilities.

Acknowledging Fear

If parents are correct in their perceptions, both family and professional actions are controlled, in part, by fear of the unknown future, the limitations of their own knowledge, and lack of control over certain events. Parents' comments in the present study were consistent with the perspectives shared by Turnbull, Summers and Brotherson (1986, p. 57), who wrote, "A major coping strategy for many families of retarded children is passive appraisal, which involves maintaining a strong present rather than future orientation, and taking one day at a time." Featherstone (1980, p. 29) expressed a similar view when she stated, "Professionals who have not themselves fought free of crippling fears sometimes misunderstand parents' efforts to safeguard the quality of their daily life. This issue can feed into the tension between parents and professionals. Teachers often complain that parents are too present-centered."

In order to cope, parents may suppress their fear, whereas professionals may mask their fear to maintain an illusion of expertise. In both cases, each party engages in behaviors that threaten to expose the fears of the other. Parents ask professionals questions for which they have inadequate answers, and professionals ask parents to engage in the potentially discomforting task of long-range planning. Potential solutions to this dilemma are far more easily proposed than accomplished. For professionals to acknowledge their fears and expose them freely will require a level of security not frequently found in public schools and will likely require a shift in professional socialization from perceived expertise to collaboration. Professionals should be increasingly aware that factors such as severity of disability, multiplicity of disability, age, life expectancy, and parental beliefs about their child's future have an impact on the family's willingness to engage in long-range planning (Vadasy & Fewell, 1986). Given these and other factors, time projections for future planning for students with disabilities must be individualized. Rather than the frequent application of environmental analysis of planning for post-school options, the future may be defined differently by each family (e.g., next year, 5 years from now, post-school). By asking parents how far into the future they wish to plan, rather than telling them to plan for post-school, educators can demonstrate their recognition that each family is individual and unique.

Dealing with the Sources of Frustration

For bureaucratic or benevolent reasons, educational service systems assign professional staff to students based on disability labels. If a child is labeled visually

impaired, a teacher for students with visual impairments is assigned. If a child has physical disabilities, a motor specialist such as an occupational or physical therapist is assigned. In the case of children with dual sensory impairments and accompanying multiple disabilities, this compartmentalized, more-is-better approach often perpetuates three major frustrations of parents: (a) too many professionals, (b) segmentation of the child based on disability labels, and (c) fragmented service coordination.

The assignment of so many professionals, each with a different speciality, often ignores the reality that the disciplines traditionally associated with students who have dual sensory impairments (i.e., special education, vision support, orientation and mobility, hearing support, audiology, speech language pathology, occupational therapy, physical therapy) have some degree of overlap in roles and functions. When team members explore potential overlaps and adopt an only-as-special-as-necessary approach to service provision, students can still access needed services while minimizing the unnecessary involvement of too many professionals (Giangreco, 1990a; Giangreco & Eichinger, 1990).

Recent evidence indicates that professionals from many disciplines typically generate an individual focus for service delivery based on what is valued by their discipline (Giangreco, Edelman & Dennis, in press). This is problematic because the ideas of group members do not converge on a shared set of goals. Rather, their potential impact is dissipated as each professional pursues a separate set of goals. The absence of a shared focus is further emphasized because teachers, parents, and specialists often disagree about who should maintain the authority for making service delivery decisions (Giangreco, 1990b). Emerging models that are "discipline-free" may address identified parental frustrations by exploring the interdependencies among disciplines, establishing individualized communication mechanisms, and offering opportunities for families to engage fully in educational service development (Benson & Turnbull, 1986; Giangreco, 1990b; Giangreco, Cloninger & Iverson, 1990; Iverson & Cloninger, 1990; Vandercook, York & Forest, 1989; Williams, Fox & Fox, 1989).

Accepting and Participating in Change

In the relatively short time since the parent interviews were completed, eight students who previously received their education in special classes or through home-based instruction (see Table 1) have been transitioned to regular class placements with special education support. This highlights the fact that change in educational placement continues to be an issue facing families. Parents often indicate having concerns about change—not only how it will affect their children, but how it might affect them (Hanline & Halvorsen, 1989). It is not surprising that parents feel left out when school systems go about

the business of enacting significant educational reforms without adequately involving them. Although extensive elaboration about the theory and practice of educational change (Bolman & Deal, 1984; Fullan, 1982), and specifically regarding school integration change (Giangreco, 1989; Lipsky & Gartner, 1989), is beyond the scope of this discussion, it is suggested that school personnel must work actively to include all relevant constituencies, including families, in changes that will affect them.

If signals are received from the school organization that change (e.g., integration) is about to take place, parents as well as professionals may benefit from opportunities to develop an anticipatory mind set, begin considering how the potential change might affect them, and to engage in reciprocal consultation with others involved in the change (Bolman & Deal, 1984). This opportunity to weigh personal costs can have a positive impact on subsequent outcomes (Cuban, 1984). Crucial considerations affecting adoption and retention of school change include both opportunities for major constituency groups to participate in planning and a realistic time frame that allows for psychological preparedness (Fullan, 1982; Sarason, 1974).

Listening to Families

Underlying everything that parents said during interviews was their concern that too often professionals do not listen to families or take into account how the children's needs are interdependent with those of other family members. The desires of parents to be trusted as authorities on their children, to be treated honestly and individually by professionals, and to expect a basic level of stability in services challenge the educational community to become increasingly reflective (Schon, 1983). In part, this reflective evaluation may highlight that what we do affects not only the children in our classrooms, but the families with whom they live. The results of this study remind us that despite platitudes about parent involvement, many parents remain dissatisfied with their level of involvement and their role in the educational process. As the 1990s begin, the success of educational programs may be determined, in part, by our ability and willingness truly to include parents as partners in education.

References

- Bailey, D. B., Winton, P. J., Rouse, L., & Turnbull, A. (1990). Family goals in infant intervention: Analysis and issues. *Journal of Early Intervention, 14*(1), 15-26.
- Baldwin, V., & Bullis, M. (1988). Prevalence data on students with deaf-blindness. In A. M. Covert & T. S. Carr (Eds.), *Value-based services for young adults with deaf-blindness* (pp. 33-40). Sands Point, NY: Helen Keller National Center for Deaf-Blind Youth and Adults Technical Assistance Center, in cooperation with The Association for Persons with Severe Handicaps Technical Assistance Project.
- Benson, H., & Turnbull, A. (1986). Approaching families from an individualized perspective. In R. Horner, L. H. Meyer, & H. D. B. Fredericks (Eds.), *Education of learners with severe handicaps: Exemplary service strategies* (pp. 127-157). Baltimore: Paul H. Brookes.
- Bogdan, R. C., & Biklen, S. K. (1982). *Qualitative research for education: An introduction to theory and methods*. Boston: Allyn and Bacon.
- Bolman, L. G., & Deal, T. E. (1984). *Modern approaches to understanding and managing organizations*. San Francisco, CA: Jossey-Bass.
- Bullis, M., & Otos, M. (1988). Characteristics of programs for children with deaf-blindness: Results of a national study. *The Journal of the Association for Persons with Severe Handicaps, 13*, 110-115.
- Carney, I. H. (1987). Working with families. In F. P. Orelove & D. Sobsey (Eds.), *Educating children with multiple disabilities: A transdisciplinary approach* (pp. 315-338). Baltimore: Paul H. Brookes.
- Covert, A. M., & Carr, T. S. (1988). *Value-based services for young adults with deaf-blindness*. Sands Point, NY: Helen Keller National Center for Deaf-Blind Youth and Adults Technical Assistance Center, in cooperation with The Association for Persons with Severe Handicaps Technical Assistance Project.
- Cuban, L. (1984). *How teachers taught: Constancy and change in American classrooms, 1890-1980*. New York: Longman.
- Daniel R. R. v. State Board of Education, F. 2d (5th Cir., June 12, 1989).
- Ellis, D. (1986). *Sensory impairments in mentally handicapped people*. San Diego: College-Hill.
- Featherstone, H. (1980). *A difference in the family: Living with a disabled child*. New York: Penguin Books.
- Ferguson, P. M., Ferguson, D. L., & Jones, D. (1988). Generations of hope: Parental perspectives on the transitions of their children with severe retardation from school to adult life. *The Journal of the Association for Persons with Severe Handicaps, 13*, 177-187.
- Fullan, M. (1982). *The meaning of educational change*. New York: Teachers College Press, Columbia University.
- Giangreco, M. F. (1989). Facilitating integration of students with severe disabilities: Implications of "Planned Change" for teacher preparation programs. *Teacher Education and Special Education, 12*(3), 139-147.
- Giangreco, M. F. (1990a). Effects of a consensus-building process on team decision-making: Preliminary data. Burlington: University of Vermont, Center for Developmental Disabilities. Manuscript submitted for publication.
- Giangreco, M. F. (1990b). Making related service decisions for students with severe handicaps: Roles, criteria, and authority. *The Journal of the Association for Persons with Severe Handicaps, 15*, 22-31.
- Giangreco, M. F., Cloninger, C., Iverson, V. (1990). *Cayuga-Onondaga assessment for children with handicaps (C.O.A.C.H.) Version 6.0*. Stillwater: Oklahoma State University, National Clearing House of Rehabilitation Training Materials.
- Giangreco, M. F., Edelman, S., Dennis, R. (in press). Common professional practices that interfere with the integrated delivery of related services. *Remedial and Special Education*.
- Giangreco, M. F., & Eichinger, J. (1990). Related services and the transdisciplinary approach: A parent/professional training module. In M. Anketell, E. J. Bailey, J. Houghton, A. O'Dea, B. Utley, & D. Wickham (Eds.), *A series of training modules for educating children and youth with dual sensory and multiple impairments*. Monmouth, OR: Teaching Research Publications.
- Goetz, L., Guess, D., & Stremel-Campbell, K. (1987). *Innovative program design for individuals with dual sensory impairments*. Baltimore: Paul H. Brookes.
- Hanline, M., & Halvorsen, A. (1989). Parent perceptions of

- the integration transition process: Overcoming artificial barriers. *Exceptional Children*, 55, 487-493.
- Helmstetter, E., Murphy-Herd, N., Roberts, S., & Guess, D. (1984). *Individualized curriculum sequence and extended classroom models for learners who are deaf and blind*. Lawrence: University of Kansas, Curriculum Development Project for Secondary Age Severely Handicapped Deaf-blind Students.
- Hill, B. K., Rotegard, L. L., & Bruininks, R. H. (1984). The quality of life of mentally retarded people in residential care. *Social Work*, 29(3), 275-281.
- Iverson, V. S., & Cloninger, C. (1990, in preparation). *Vermont integration planning process (VIIP)*. Burlington: University of Vermont, Center for Developmental Disabilities.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Lipsky, D. K. (1989). The roles of parents. In D. K. Lipsky & A. Gartner (Eds.), *Beyond separate education: Quality education for all* (pp. 159-179). Baltimore: Paul H. Brookes.
- Lipsky, D. K., & Gartner, A. (1989). Building the future. In D. K. Lipsky & A. Gartner (Eds.), *Beyond separate education: Quality education for all* (pp. 255-290). Baltimore: Paul H. Brookes.
- McGonigel, M. J., & Garland, C. W. (1988). The individual family service plan and the early intervention team: Team and family issues and recommended practices. *Infants and Young Children: An Interdisciplinary Journal of Special Care Practices*, 1(1), 10-21.
- Meyer, L. H., & Eichinger, J. (1987). Program evaluation in support of program development: Needs, strategies, and future directions. In L. Goetz, D. Guess, & K. Stremel-Campbell (Eds.), *Innovative program design for individuals with dual sensory impairments* (pp. 313-353). Baltimore: Paul H. Brookes.
- Patton, M. Q. (1980). *Qualitative evaluation methods*. Beverly Hills, CA: Sage.
- Powell, T. H., & Ogle, P. A. (1985). *Brothers and sisters: A special part of exceptional families*. Baltimore: Paul H. Brookes.
- Sarason, S. (1974). *The culture of the school and the problem of change*. Boston: Allyn & Bacon.
- Schalock, R. L. (1990). *Quality of life. Perspectives and issues*. Washington, DC: American Association on Mental Retardation.
- Schon, D. A. (1983). *The reflective practitioner: How professionals think in action*. New York: Basic Books.
- Stainback, S., Stainback, W., & Forest, M. (1989). *Educating all students in the mainstream of regular education*. Baltimore: Paul H. Brookes.
- Taylor, S. J., & Bogdan, R. (1984). *Introduction to qualitative research methods. 2nd edition*. New York: John Wiley and Sons.
- Turnbull, A. P., Summers, J. A., & Brotherson, M. J. (1986). Family life cycle: Theoretical and empirical implications and future directions for families with mentally retarded members. In J. J. Gallagher & P. M. Vietze (Eds.), *Families of handicapped persons: Research, programs, and policy issues* (pp. 45-65). Baltimore: Paul H. Brookes.
- Turnbull, A. P., & Turnbull, H. R. (1990). *Families, professionals, and exceptionality: A special partnership (second edition)*. Columbus, OH: Merrill Publishing.
- Vadasy, P. F., & Fewell, R. R. (1986). Mothers of deaf-blind children. In R. R. Fewell & P. F. Vadasy (Eds.), *Families of handicapped children: Needs and supports across the life span* (pp. 121-148). Austin, TX: Pro-Ed.
- Vandercook, T., York, J., & Forest, M. (1989). The McGill Action Planning System (MAPS): A strategy for building the vision. *The Journal of the Association for Persons with Severe Handicaps*, 14, 205-215.
- Vermont Department of Education (1987). *Guidelines for identification of students with dual sensory (vision and hearing) impairments in the state of Vermont*. Montpelier: Vermont Department of Education. Author.
- Williams, W., Fox, W., Christie, L., Thousand, J., Conn-Powers, M., Carmichael, L., Vogelsburg, R. T., & Hull, M. (1986). Community integration in Vermont. *The Journal of the Association for Persons with Severe Handicaps*, 11, 294-299.
- Williams, W., Fox, T., & Fox, W. (1989). *Integrating the instruction of students with intensive educational needs into regular education classrooms: Individual program design procedures manuals*. Burlington: University of Vermont, Center for Developmental Disabilities.

Received: June 18, 1990

Final Acceptance: September 21, 1990

Editor in Charge: Lori Goetz