Shifts in Parent–Therapist Partnerships: Twelve Years of Change

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KEY WORDS
• children with developmental disabilities
• pediatrics
• survey

OBJECTIVE. A national survey was conducted to identify occupational therapists' current attitudes and values in their working relationships with parents of preschool children with developmental disabilities. This study replicated a 1987 national survey that examined therapists' relationships with parents of preschool children with cerebral palsy.

METHOD. Surveys were sent to a random sample of 400 therapists, with 199 returned from respondents who identified themselves as working with preschool children with developmental disabilities. After calculating descriptive statistics for each item in the survey, a one-way analysis of variance was performed to test for differences based on four demographic variables.

RESULTS. Respondents reported that working with parents, more than any other aspect of intervention, had the greatest impact on the progress of a child with disabilities. Consistent with the 1987 survey, respondents believed that parents focus on their own adjustment to their child's disability as well as on their child's progress more than any other issues. Therapists continue to report satisfaction when generating positive change for child and parent through education and use of clinical knowledge and skill.

CONCLUSION. Results suggest that efforts to foster family-centered intervention in occupational therapy educational programs are increasing therapists' confidence and skills in working with parents of children with disabilities. Implications for occupational therapy practice and education include a need for therapists to expand their knowledge and expertise in working effectively with vulnerable families. Educators need to focus on teaching strategies not only to refine the role of occupational therapy as a direct treatment provider, but also to incorporate creative ways to deal with the psychosocial issues of parents and families.


Hinojosa, Anderson, and Ranum (1988) reported on a national survey that investigated the roles of occupational therapists working with parents of preschool children with cerebral palsy. Although the majority of respondents believed that they were competent in working with parents, they did not believe that the basic professional education in occupational therapy had adequately prepared them. Hinojosa et al. concluded that therapists could benefit from expertise in counseling and training to work collaboratively with parents. The purpose of the present study was to replicate the original study to identify current occupational therapists' attitudes and values in their working relationships with parents of preschool children with developmental disabilities after 2 decades of legislative support (Individuals With Disabilities Education Act of 1990 [IDEA, Public Law 101–476]; IDEA Amendments of 1991 [Public Law 102–119]; IDEA Reauthorization of 1997 [Public Law 105–117]) and educational efforts (Brewer, McPherson, Magrub, & Hutchins, 1989; Dukewitz & Gowan, 1996; Dunst, Trivette, & Deal, 1988; Filer & Mahoney, 1996; Hinojosa, Moore, Sabari, & Doctor, 1994).
Research (Humphry, Gonzalez, & Taylor, 1993; Judge, 1997; Lamorey & Ryan, 1998; Noojin & Wallander, 1996) and other reports in the literature (Filer & Mahoney, 1996; Lawlor & Mattingly, 1998; Thompson et al., 1997) have discussed the value of family involvement in intervention. In family-centered intervention, the focus of intervention is guided by the needs of the entire family (Dunst, Trivette, & Deal, 1994; Filer & Mahoney, 1996; Humphry & Case-Smith, 2001; Malone, 1997; Rosenbaum, King, Law, King, & Evans, 1998). When family-centered care guides intervention, therapists support each family member’s natural roles to foster effective intervention. In this approach, family members are valued and considered to be equal to the professionals as members of the intervention team (Brewer et al., 1989; Hinojosa et al., 2001). As Lawlor and Mattingly (1998) pointed out, involving family members in therapy has not been added easily to the therapist’s practice, especially when contemporary service delivery systems value therapeutic interventions that account only for the child’s specific needs.

The importance of collaborative family–therapist relationships is now readily accepted (Filer & Mahoney, 1996; Humphry & Case-Smith, 2001; Lawlor & Mattingly, 1998). Given this acceptance, researchers need to examine more closely the distinct characteristics of parent–therapist relationships. In a recent study of 10 Australian families receiving early intervention services for their children between 2 and 5 years of age, Thompson (1998) concluded that involvement with families creates a greater time demand for the professional and often can lessen hands-on time with the children. The mothers in this study reported that the amount of intervention time their children received from therapists affected their children’s development. They also believed that increased frequency of service combined with more time reinforcing therapy at home would improve their children’s progress. Additionally, they wanted reassurance and feedback from their service providers about their children. Finally, these mothers emphasized the need for informal support within an open and friendly relationship with their children’s therapists. These findings corroborate the conclusions of earlier studies (Brown, Humphry, & Taylor, 1997; Case-Smith & Nastro, 1993; Hinojosa, 1990; Humphry & Thigpen-Beck, 1998).

Since the 1970s, legislation has mandated family-centered care for programs and services to children with disabilities (Walker, 1992). Professional efforts within the past 10 years have supported the goal that the education of therapists should include the acquisition of the knowledge and skills needed for family-centered practice (Hinojosa et al., 1994; Humphry & Link, 1990; Schaaf, & Mulrooney, 1989). Because research and legislation support the importance of parent–therapist partnerships, it is advantageous to explore the current attitudes and values of occupational therapists working with parents of preschool children with developmental disabilities. The present study replicated a 1987 national survey that examined therapists’ relationships with parents of preschool children with cerebral palsy. This study broadened the scope to include the parents of preschool children with developmental disabilities. The purpose of this study was to identify current occupational therapists’ attitudes and values in their working relationships with these parents after 12 years of legislative support. Data also were collected on occupational therapists’ perceptions of parents’ needs and roles.

**Method**

A mailed questionnaire was used to collect data from a random national sample of 400 occupational therapists. A pilot study was conducted to refine the questionnaire. To examine the roles of occupational therapists working with parents of preschool-age children with cerebral palsy, the questionnaire originally developed by Hinojosa et al. (1988) was revised using current terminology and expanded to address issues for parents of children with a broader range of disabilities. The revised five-page questionnaire consisted of 59 items on (a) demographics, (b) occupational therapists’ attitudes toward working with parents, and (c) occupational therapists’ roles with parents. Survey items varied and were written using rank order, rating scales, and open-ended questions. Respondents were instructed both in the cover letter and throughout the questionnaire to answer questions only as they related to their practice with parents of preschool children with developmental disabilities. This survey was conducted according to the procedures outlined by Dillman (2000) and Babbie (1990).

**Validity and Reliability of the Questionnaire**

An expert group of 15 pediatric occupational therapists examined the instrument for face and content validity by completing the survey and a critique form. Thirteen (93%) had practiced for more than 7 years, 12 held master’s degrees, and 1 held a doctorate. The critique form asked for their input on the length of time taken to complete the survey, the accuracy of the terminology, the relevance of the questions, and the clarity of the questions and instructions. The therapists reported that the survey took between 15 min and 30 min to complete. On the basis of feedback, some directions were clarified and some were refined to improve clarity and readability. A Cronbach’s alpha was used to examine the internal consistency of the pilot data for the first two sections on attitudes and parent–therapist
issues. An alpha of .77 was found for these sections, leading to the acceptance of the items as a reliable composite instrument. Test–retest reliability was not determined.

Sample and Procedure

The questionnaire; a cover letter describing the nature of the study; a request form for receipt of results; and a stamped, self-addressed envelope were mailed to a random sample of 400 registered occupational therapists who were members of the Developmental Disabilities Special Interest Section of the American Occupational Therapy Association in 1998. The sample was selected by computer from those members who had stated that they work with children from birth to school age. Follow-up letters were sent through first-class mail to nonrespondents 6 weeks and 12 weeks after the first mailing. At 16 weeks, a final follow-up letter, another survey, and postage-paid return envelope were sent to nonrespondents.

Data Analysis

A total of 327 (81.8%) of the 400 questionnaires were returned. Of these, 125 (31.3%) were unanswered because the respondents did not currently work with preschool children with developmental disabilities, and 3 were returned because of incorrect addresses. Responses from the 199 therapists remaining formed the database of this survey. Respondents represented 46 states. Some did not answer all the questions, and some did not answer questions according to the instructions. Thus, the tables in this article are based on varying numbers of respondents. Totals, therefore, also varied with the number of accurately completed responses.

Data were coded and analyzed using the Statistical Package for the Social Sciences, Version 10.0 (SPSS, 2000). Descriptive statistics were used to analyze and report the data. Demographic differences among respondents were analyzed using chi-square analysis for independence at the alpha level of .05. After calculating descriptive statistics for each item in the survey, a one-way analysis of variance (ANOVA) was performed for four demographic variables (i.e., therapist age, place of practice, years in pediatrics, degree attained) to determine whether total scores on the survey differed significantly on the basis of these independent variables.

Results

Data from the survey provided information in five areas: (a) demographic information on the occupational therapists; (b) occupational therapists’ attitudes toward working with parents; (c) occupational therapists’ perception of the attitudes, concerns, and needs of parents; (d) occupational therapists’ roles with parents; and (e) issues, difficulties, and satisfactions that arise from therapists’ working relationships with parents.

Demographic Information

All respondents had earned bachelor’s degrees. The highest earned academic degree of almost two thirds was a bachelor’s degree (n = 122, 61.2%); more than one third (n = 72, 36.7%) had earned master’s degrees; and 2 (1%) had earned doctoral degrees. More than one third (n = 75, 38.1%) worked in educational institutional settings, such as preschools or schools; 25 (12.7%) worked in private practices; and 25 (12.7%) worked in home-based therapy situations. Respondents were predominantly female (n = 192, 97%) and ranged in age from 23 to 68 years (M = 37.9 years, median = 38 years, SD = 10.08). Eighty-seven (44%) had worked more than 10 years in pediatrics and were advanced practitioners. More than half (54.9%) indicated that they were parents.

Factors Occupational Therapists Consider Important in Working With Parents

Each respondent ranked his or her agreement with statements on issues related to working with parents (e.g., occupational therapists work most effectively with parents who appear invested in their child’s progress, occupational therapists do not have enough time to spend with parents) on a forced-choice Likert scale of 1 (strongly agree) to 4 (strongly disagree). Most of the respondents agreed that they worked more effectively with parents who were invested in their child’s progress (see Table 1). Most also reported that they considered working with parents to be an important aspect of occupational therapy intervention and that its importance has not been overemphasized.

Almost three quarters of the therapists (72.5%) reported that their basic professional education adequately prepared them to work with parents. More than three quarters (76.6%) believed that working with parents has a greater impact on a child with disabilities than any other aspect of intervention. The majority (59.4%) believed that therapists do not have enough time to spend with parents. Analyses of responses to two other items were equally distributed (agree, disagree). Those two items were “parents do not have enough time to spend with parents” and “parents’ feelings toward their child’s disabilities interfere with intervention objectives.”

Perceptions of Issues Important to Parents

From a list of common issues relevant to having a child with developmental disabilities, respondents were asked to iden-
tify and rank three issues that most commonly arose during their interactions with parents (see Table 2). The issue ranked first by 29.7% was parents’ adjusting to their child’s disabilities. The issue ranked second by 26.6% was the child’s progress in therapy. The importance of the two highest ranked issues becomes evident when the total number of respondents rating these issues as first, second, and third most common is combined. These combined numbers of respondents indicate that 61.5% selected progress in therapy and 54.7% selected parents adjusting to their child’s disability as issues frequently arising during parent–therapist interactions. The distribution of the rank for other issues listed did not indicate that any arose with consistent frequency (see Table 2).

Table 3 summarizes respondents’ perceptions of parental concerns about the child’s progress by asking them to rank order six concerns. Ambulation was ranked as the highest parental concern by 96 (49.5%) respondents. A total of 129 respondents selected ambulation as either their first or their second most common parental concern. A total of 114 selected speech and language development as either their first or their second most common parental concern. Almost half (49.5%) selected concerns about the child’s future as the least important concern.

Role of Occupational Therapists With Parents

Of the 199 respondents, 170 estimated percentages of time they spent in selected activities with parents from a fixed list (see Figure 1). When the percentages of time spent on activities that involved the child’s therapeutic program are combined (discussing the child’s disability, teaching techniques, home programming, home management, discussing the child’s behavior and preschool placement), it appears that the respondents spend two thirds of their time (66.4%) instructing parents about the care of their child. They estimated that they spent 30% of their time discussing all parent-directed concerns, including parental needs and feelings, play activities, and social and personal discussions.

Respondents rated on a 4-point scale (not important, somewhat important, very important, essential) the importance of listed parent-related factors when treating a preschool child with disabilities. They reported that it was essential to explore parental goals, help parents to understand therapists’ roles, provide information about the abili-
ties of the child, and instruct parents on home programs. Providing support and information on advocacy programs and support groups were valued but believed to be less essential.

**Demographic Analysis**

Four items on the survey were demographic in nature—degree attained, age of therapist, place of practice, and years of practice in pediatrics. Responses for all survey items that were not demographic in nature were summed, and this total was analyzed for significant differences within each of the four demographic variables using a one-way ANOVA (SPSS, 2000). One of the four demographic items—6 years or fewer or 7 years or more of practice in pediatrics—achieved significance at the .05 level, $F(1, 197) = 4.064, p = .019$, indicating a significant difference between the total sum of scores on survey items between these two groups. Respondents with more years of experience reported that working with parents had the greatest influence on a child’s progress. No significant differences were found among sums of scores based on age (37 years or older), degree attained, or place of practice, although age was near statistical significance probably because it is highly correlated with the more salient factor of years in pediatric practice.

**Occupational Therapists’ Experienced Difficulties and Satisfactions Working With Parents**

Responses to two open-ended questions were analyzed for recurring themes and to gather descriptive data regarding the difficulties and satisfactions the respondents experience while working with parents. The first question asked, “What are the three most difficult issues to deal with that you have experienced in working with parents?” The respondents listed many difficulties from which several consistent themes emerged. Dealing with parent denial was a major theme and viewed as a formidable challenge for therapists. Within this theme, respondents discussed parents’ “unrealistic” expectations and their “inability to recognize the needs of their children.” Another theme was parental noninvolvement, where respondents reported that parents often expected others to assume care of their child and that they did not follow through with recommendations. Included in this theme were inconsistent attendance to therapy, lack of respect for the therapist’s knowledge, and lack of children’s progress in therapy. The final theme evolved from social issues that affect the therapeutic process. Respondents discussed parental stress, poor financial resources, unstable family units, poor parenting skills, lack of community resources, limited social interactions with others, and poor parent accessibility as obstacles to working effectively with parents.

Responses to the second question, which asked respondents to identify the most satisfying experiences they had working with parents, supported the notion that therapists find it satisfying to generate change for the child and parent through education and the use of clinical knowledge and skills. The respondents reported satisfaction when the parent placed trust in their professional judgment and, therefore, in the parent–therapist relationship. One of the respondents described fostering a parent–therapist relationship as “parent empowerment.” Parent appreciation of the therapist’s efforts, the child’s observable progress, and parent acceptance of the child’s disability were reported as other satisfying experiences.

**Discussion**

A national survey examined 199 occupational therapists’ attitudes and values related to their interactions with parents of preschool children with disabilities. This study replicated an earlier national survey that examined therapists’ relationships with parents of preschool children with cerebral palsy (Hinojosa et al., 1988).

In the 1988 study, 85% of respondents reported that they did not believe that their basic professional education had prepared them to work with families. In contrast, almost three quarters (72.5%) of the respondents in the current study stated that they believed their professional education did prepare them to work with families that had a child with a disability. This finding suggests that basic pro-
fessional education programs are better preparing occupational therapists with the necessary skills to work appropriately with parents of a child with disabilities. As in the prior study, the respondent sample consisted of experienced therapists; 44% had more than 10 years of experience working in pediatrics. It is possible that work experience as well as formal educational training contributed to beliefs that they were prepared and effective at collaborating with family members.

In both studies, respondents reported their beliefs that parents consider their children’s progress to be critically important. This finding suggests that therapists are providing services in conjunction with parents’ concerns when they focus interventions to address a child’s specific deficit and are concerned with the child’s progress in deficit areas. In most cases, a child is referred to occupational therapy because of a specific performance skill deficit; therefore, it is reasonable to infer that therapists would implement interventions to address the specific deficits. Further, it is logical that parents are focused on their children’s services that assess the identified primary deficits. The current study revealed that respondents maintain that the amount of time therapists spent with a child is as important as the time they spent working with parents and other family members. Yet, more than three quarters (76%) agreed that the time they spent with parents had a greater impact on a child than any other aspect of intervention.

Therapists’ perceptions of issues important to parents have remained the same in the past 12 years; in both studies, respondents reported ambulation followed by speech and language as primary concerns for parents of preschool children with disabilities. As in the prior study, respondents reported that a child’s future was of least concern to parents. Given the age group that respondents were asked to consider—preschool children with developmental disabilities—it would make sense that parents focus their concerns on their child developing the ability to walk and talk rather than on their child’s future. Lawlor and Mattingly (1998) proposed that parents and therapists have a different sense of time. Based on their analysis of parent narratives, they concluded that parents are more future oriented than therapists. Because these survey data were collected from therapists, it would be appropriate to interview or survey parents of preschool children with disabilities about what issues are important to them. If, in actuality, parents and therapists have different perceptions of time horizons as reported by Lawlor and Mattingly, then therapists may need to reexamine their belief that parents of preschool children are more focused on the more immediate developmental goals for their children as these survey data suggest.

Parents’ own ability to adjust to their child’s disability and their interest in the progress of their child continue to be the most common issues therapists face in interacting with families. When respondents rated their actual time spent with parents, 66.4% of the time was spent instructing the parent in matters regarding the child’s therapeutic program. Thirty percent of therapists’ time is spent discussing affective issues, such as parent needs, feelings, and concerns. These findings supported the previous study in reiterating therapists’ perceptions of the importance parents place on understanding their child’s disability and the progress of their child. During their child’s therapy, parents often become more knowledgeable about deficits. The child’s progress in deficit areas is one of the central issues therapists discuss with families throughout intervention.

When respondents were asked about the amount of time they spend on specific activities with parents, the results demonstrate that therapists still spend a significant amount of time reviewing home instructions and teaching handling and positioning techniques. Consistently, respondents reported that they spend less time focusing on the child’s other needs and the parental needs and concerns. Lawlor and Mattingly (1998) pointed out that it is difficult to maintain the role of expert while trying to connect interventions with the expressed needs of the family. Further, they discussed the fact that the nature of therapeutic intervention requires that therapists focus on problem setting and identification, assessment, treatment options, and treatment efficacy. When working with families, therapists must balance their time and efforts between focusing directly on the child’s needs and addressing family member’s needs.

As in the prior study, when assessing difficulties and satisfactions in their roles as therapists, respondents reported difficulty with parental denial and unrealistic expectations. They also were dissatisfied when parents did not follow through with recommendations. A relatively new finding from this survey suggests that therapists find difficulty working with parents who face multiple stressors, such as unstable family units, poor parent accessibility, parent stress, lack of financial resources, poor parenting skills, and limited social interactions of parent and family. These issues may affect attendance, consistency of intervention, payment, and carryover of intervention goals. Accessibility to parents, parents under stress, and limited resources challenge therapists’ abilities to work in partnership with parents. Although some respondents avoid involvement with family issues in treatment intervention, they are aware that these issues affect the child. Studies indicate that early academic difficulties, attachment disorders, conduct problems, poor social skills, and poor problem-solving abilities often are common for children living in vulnerable families (Keenan & Wakschlag, 2000; Knitzer, 2000; Webster-
Stratton, 1998). Helping parents with resources, knowledge, and support necessary to meet their child and family needs is empowering to parents.

Respondents reported satisfaction when parents were actively involved in the child’s therapy program and followed their recommendations. They also reported that being appreciated and respected for their knowledge was important to them. Respondents described themselves as feeling more effective when the child has made observable progress and when the parent accepts the child’s disability. They also believe that they could be more effective when they provided parents with information and strategies to make decisions and when parents actively participated in their child’s intervention program. Parents are better able to meet their own needs and the needs of their child when they are able to exercise some control and decision making about solutions to problems and the resolution of concerns (Cauthen & Knitzer, 1999; Dunst et al., 1994; Galinsky, Shubilla, Willer, Levine, & Daniel, 1994).

The results of this survey suggest positive changes in therapists’ perceptions of their preparation and skills for working effectively in partnerships with the parents of a child with a disability. These encouraging changes provide educators and clinicians with an exciting opportunity to further work in partnership with parents in developing effective, collaborative relationships.

Beyond appreciating the importance of family-centered care, educators may wish to focus on teaching strategies for developing collaborative skills. Further, educators may want to address new areas of concern, including dealing with parents who are perceived to be in denial, have unrealistic expectations, or show poor recognition their child’s needs. We therapists need to better understand these processes by examining what is meant by denial or what determines what is unrealistic. Further, the respondents’ comments challenge the profession to expand our knowledge and expertise to support families as they deal with family stress, limited social interactions, and financial constraints.

This study represents the views of experienced occupational therapists treating preschool children with developmental disabilities. The majority of respondents were women who claimed to work mostly with mothers. Because therapists reported working primarily with mothers, the survey results may be most relevant to the relationship between occupational therapists and mothers of preschool children with developmental disabilities.

This study has several limitations. First, the sample, although randomly selected, included a large number of respondents who did not work with preschool children with disabilities. Therefore, although 327 (81.8%) surveys were returned, only 199 formed the database for this study. Sampling error resulted in 125 misidentified therapists who did not currently work in pediatrics. Second, a limitation in terms of the survey development was that test–retest reliability was not done. Finally, the results of this study are limited to therapists’ interactions with parents of preschool children; therefore, the findings cannot be generalized to all therapists who work with parents. Even with these limitations, the present study provides evidence that occupational therapists have increasing confidence and skills in working with parents of preschool children with developmental disabilities.

Occupational therapists who work with children with disabilities are in a unique position to facilitate family-centered intervention. This study’s findings suggest that occupational therapists recognize the importance of working with parents and that they feel more confident about their skills than they did 12 years ago. At the same time, therapists acknowledge the complexities of developing effective partnerships in the current service delivery systems. The data from this study provide evidence of the positive changes in therapists’ knowledge, beliefs, and attitudes toward working with parents that underlie the basis of family-centered care. Research is needed to validate this study’s findings and to examine actual practices. Ethnographic studies are needed to enrich our understanding of parent–therapist interactions and validate the findings of this study. Finally, although this study supports the view that occupational therapists may be increasingly competent in working with families, additional research is needed to examine what educational programs are most effective. Occupational therapists need to continue to be creative when working with parents who have children with developmental disabilities. Methods of service delivery, funding and payment, and therapeutic goals need to be adapted to meet each unique family and child’s needs.

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