Parents’ Perceptions of Motor Interventions for Infants and Toddlers With Down Syndrome

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The purpose of the study was to analyze parents’ perceptions of their participation in a university-directed, parent-implemented, home-based pediatric strength intervention program as (a) one approach to evaluating the effectiveness of a program conducted over a 4-year period with families of infants and toddlers with Down syndrome and (b) a means of deriving guidelines for future early intervention programs. Participants were 22 parents from 11 families of children with Down syndrome; the children ranged in age from 6 to 42 months. Participatory evaluation research, semistructured audio recorded home interviews, and qualitative content analysis were used. The results indicated that the parents (a) perceived themselves as being empowered to implement the program, (b) perceived their expectations about improved motor development of their children had been met, and (c) perceived the program was worthwhile. The parents’ perceptions provided meaningful evaluation data that enabled the development of guidelines for future pediatric strength intervention programs.

Preparing parents as teachers or cointerventionists has been an integral part of early intervention programs for several decades (Beelmann & Brambring, 1998; Bronfenbrenner, 1974; Bruder & Bricker, 1985; Cartwright, 1981; Kaiser, Hancock, & Hester, 1998). Early intervention models usually involve home-based services, center-based services, and/or services delivered in a private group or family childcare setting (Mowder, 1997). Services commonly occur from 15 to 60 min for weekly, bimonthly, or monthly visits, depending on the needs of the child and...
family and the availability of services. Direct services to the child are typically interrupted if the interventionist or the family is unable to keep the appointment.

Adapted physical educators have been interested in infant and toddler interventions since the late 1980s. Cowden and Eason (1991) recommended the creation of pediatric adapted physical education (PAPE) as a subfield within adapted physical education. Although few adapted physical education personnel preparation programs currently exist that emphasize the infant and toddler age-range, general consensus abounds regarding the benefits of movement programs for infants and toddlers with disabilities (Houston-Wilson, 2000). This consensus is evidenced in a special issue of *Adapted Physical Activity Quarterly* on developmental delay in infancy and early childhood (Block & Davis, 1996; Connor-Kuntz & Dummer, 1996; Goodway & Rudisill, 1996; Sayers, Cowden, Newton, Warren, & Eason, 1996; Tarr & Pyfer, 1996; Zittel & McCubbin, 1996) and the inclusion of entire chapters or at least significant sections on infants and toddlers in the most recent editions of adapted physical education textbooks (e.g., Auxter, Pyfer, & Huettig, 2001; Burton & Miller, 1998; Cowden, Sayers, & Torrey, 1998; Dunn, 1997; McCall & Craft, 2000; Sherrill, 1998; Winnick, 2000). The recent compilation of research on perceptual-motor behavior in Down syndrome also includes information on infants and toddlers (Weeks, Chua, & Elliott, 2000).

Two long-term infant and toddler programs conducted by physical educators and motor development specialists have generated published research on Down syndrome. One was begun by Ulrich and Ulrich (1995) at Indiana University and now continues at the University of Michigan. The other was begun by Cowden at the University of New Orleans (Sayers et al., 1996) and continued there until recently. Based on previous research regarding the process through which young children with Down syndrome learn to walk (Ulrich & Ulrich, 1995; Ulrich, Ulrich, Collier, & Cole, 1995), Ulrich and Ulrich (1999) developed a home-based approach to early intervention for infants with Down syndrome. The theoretical basis of this work was dynamic systems theory (Ulrich, 1997). The researchers studied 30 infants with Trisomy 21 beginning at the time they could sit independently for 30 s (thus, ages varied). The intervention consisted of parent-administered training of their child on an infant treadmill 5 days per week for 8 min each day until independent walking was achieved. Progress was monitored through biweekly pediatric physical therapy, biweekly observations of new motor behaviors and changes in physical growth by the researchers and others, and a gauge on the infant treadmill. The experimental group (*n* = 15) walked independently an average of 101 days earlier than the control group (*n* = 15).

Sayers et al. (1996) observed changes in the walking patterns of 5 infants and toddlers, ages 18 to 38 months, with Down syndrome, who participated in an individualized 8-week home-based pediatric strength intervention (PSI) program at the University of New Orleans. Parents learned exercises at the university and then implemented an exercise program at home 4 or more days per week. The length of the home-based intervention sessions varied for each child according to the individualized exercises and factors that influenced motivation to participate on any given day. Improved walking patterns were observed for 4 of the 5 infants. The theoretical basis of the exercises used during the PSI was progressive interactive facilitation, defined by Cowden et al. (1998) as a combination of
neurodevelopmental patterning and proprioceptive stimulation delivered through sequential interactive exercises designed to facilitate tone, strength, and balance. The PSI program was evaluated by various methods (Cowden et al., 1998). The research of Sayers et al. (1996) and the present study are aspects of this program evaluation.

A thorough program evaluation includes some determination of family participation or satisfaction. Parental input is often used to evaluate early intervention programs (Able-Boone, Sandall, Loughry, & Frederick, 1990; Caro & Derevensky, 1991; McBride, Brotherson, Joanning, Whidden, & Demmitt, 1993; Upshur, 1991). Through parent report measures, for example, Miller (1992) documented that families of children with Down syndrome accurately report their children’s vocabulary size. These parents’ realistic views of their children’s development lends support to the practice of listening to parents’ voices through program evaluation efforts. Bailey et al. (1998) suggested that responses to written evaluation instruments are limited to the choices provided on the instrument and that it would be extremely tedious and cumbersome to design an instrument to measure all of the various differences among families. Bailey et al. (1998) recommended that interview or direct observation strategies be employed when evaluations include parents or families. Bailey et al. (1998) and Powell (1988) acknowledged the dilemma of early intervention program evaluation design: Case studies take a significant amount of time to collect and describe and lack widespread generalization to other families, yet global treatment-control groups are difficult to design and implement because of the diversity of children with disabilities and their families.

The basic belief driving the present study was that parents who participated in a university-directed, parent-implemented, home-based pediatric strength program should be actively involved in the evaluation of the program. Like Patton (1990), we conceptualized evaluation broadly as including “any effort to increase human effectiveness through systematic data-based inquiry” (p. 11). Evaluation, for the purpose of this study, was defined as the process of judging or determining the significance, worth, or quality of a program (Worthen, Sanders, & Fitzpatrick, 1997). According to Idol, Nevin, and Paolucci-Whitcomb (1994), the criteria that should guide evaluation are effectiveness, efficiency, and affectiveness. Effectiveness refers to achievement of goals. Efficiency refers to cost of achievement in terms of energy, time, money, and other resources and is sometimes conceptualized as strengths and weaknesses of a program. Affectiveness refers to feelings in regard to participation (e.g., good or bad, beneficial or nonbeneficial, enjoyable or not enjoyable, satisfied or not satisfied, empowered or not empowered).

Our purpose was to analyze parents’ perceptions of their participation in a university-directed, parent-implemented, home-based PSI program as (a) one approach to evaluating and improving a program conducted over a 4-year period with families and infants and toddlers with Down syndrome and (b) a means of deriving guidelines for developing and evaluating future early intervention programs. Perceptions were operationally defined as the processes and products of decoding or obtaining meaning (Sherrill, 1998) from participation in the program, as revealed by answers to interview questions that ask about feelings, expectations, strengths, and weaknesses. The processes and products that comprise perception are typically interwoven and expressed as opinions, beliefs, and feelings (Krech, Crutchfield, & Livson, 1969).

Following are research questions that guided this study:
1. Did parents perceive themselves as being empowered to implement the PSI program independent of university staff?
2. Did parents perceive that their expectations about improved motor development of their children had been met?
3. Did parents perceive that the university-directed, parent-implemented, home-based PSI program was worthwhile?
4. What recommendations did parents make concerning parent involvement in the delivery of services to infants and toddlers with disabilities?

We believed that if the answer to each of the first three questions was a “yes,” the program should be evaluated as effective, efficient, and positive in affect. This would mean that parents perceived that goals were met; that time, energy, and money expenditures were in balance with perceived outcomes; and that feelings about the program were good.

Method

Our approach to the program evaluation was participatory evaluation. According to Cousins and Earl (1995), “Participatory evaluation is best suited to formative evaluation projects that seek to understand innovations (programs) with the expressed intention of informing and improving their implementation” (p. 8). This approach mirrors our intention to gather information relative to improving a unique program for delivery of early intervention services. It also embraces our belief that the program participants are well suited to offer significant contributions to our evaluation (Worthen et al., 1997). Evaluation can be quantitative or qualitative or both (Worthen et al. 1997). In this study, we chose to use a qualitative method (i.e., to examine perceptions of parents about effectiveness, efficiency, and affectiveness by asking questions about feelings, expectations, strengths, and weaknesses). This decision is supported by such experts as Patton (1990) and Reason (1994).

Participants

Our sampling goal was to include as many families as possible who had enrolled in the PSI from 1994 to 1998 and who would consent to give an interview. The sampling design was purposive in that families had to meet criteria for enrollment in the PSI program: (a) the infant or toddler had Down syndrome and (b) there was the ability to pay $35.00 for the 8-week clinic. We asked all 30 parents of these families \( n = 15 \) to participate in this study and mailed them a description of the study and a consent form. The consent form stated that participation was voluntary and would not affect their family’s continued participation in the PSI program. Of the 22 parent participants (11 families) who returned consent forms, 3 families were from the original research by Sayers et al. (1996).

Researchers made every effort to protect the confidentiality of participants. Pseudonyms were used to identify participants. Demographic data were collected to situate the study, its findings, and recommendations for future research. These data are presented in Table 1.

We asked the participants to identify themselves as either the child’s primary interventionist or supporting interventionist based on how often they participated in the home-based delivery of the intervention. The primary interventionist
was defined as the parent who implemented the child’s PSI most frequently and for the longest amount of time. The supporting interventionist was defined as the parent who supplemented the primary interventionist’s implementation of the PSI.

All mothers identified themselves as the primary interventionist. The fathers were supporting interventionists. Because of this finding, we have used the terms mothers and fathers in this report rather than primary and secondary interventionists.

Family units tended to be relatively similar to each other. Ten of the 11 family units described their ethnicity as Caucasian. One family described its ethnicity

Table 1 Demographic Data Related to the Pediatric Strength Intervention (PSI)

<table>
<thead>
<tr>
<th>Parent</th>
<th>Age</th>
<th>Education</th>
<th>Family income</th>
<th>Semesters of PSI</th>
<th>Child’s age (months)</th>
<th>Child’s gender</th>
<th>No. of semesters since last PSI</th>
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Note. Mo = mother; Fa = father. Parent’s age at time of interview. Income: 1 = High school; may or may not have attempted to complete bachelor’s degree; 2 = bachelor’s degree; 3 = master’s degree or higher. 1 = Family income of $15,000 to $24,999 per year; 2 = family income of $25,000 to $49,999 per year; 3 = family income of over $50,000 per year. Number of 8-week PSI clinics family completed. Child’s age at beginning of first semester enrolled in clinic. Number of academic semesters (Fall, Spring, Summer) since the family last participated in a PSI clinic. This child first participated for one semester when he was 22 months old; he later participated when he was 42 months old.
as Black American. Nineteen of the 22 participants had some college experience. The parent participants’ ages ranged from 30 to 49 years, $M = 38$. All of the fathers and 8 of the mothers were employed during their participation in the PSI. Eight families had incomes of $25,000 or above. Four of the mothers indicated that they taught the exercises to someone else who assisted them with implementing the PSI. The helpers for 2 of these mothers were siblings of the child with Down syndrome. The helpers for the other 2 mothers were the child’s daily babysitter. In one instance, the babysitter was the maternal grandmother.

All of the parents indicated that their child participated in other early intervention programs at some point while they also participated in the PSI. For each family, the other programs included early intervention special instruction and physical therapy. One family also received speech therapy, and another family also received occupational therapy. Seven families received the services of all four professions.

Instrument

A semistructured interview was developed in accordance with the recommendations of Gorden (1980), Patton (1987), and Rubin and Rubin (1995). This allowed each parent to direct his/her own answers in a manner that was similar to a conversation while also allowing the researchers to obtain information believed to be relevant to evaluation of the program. The purpose of the interview was to gather the information, perspectives, personal views, complexity, and meaning from the parents without unduly influencing their perceptions (Rosenblatt & Fischer, 1993).

Five experts independently reviewed the interview questions and judged them to be appropriate and relevant, and pilot testing with parents confirmed the judgment of the experts. The experts were two professionals in adapted physical education, one professional in early childhood education, one curriculum theorist, and one program evaluator. Criteria used in the selection of the experts were (a) 15 or more years of experience in program development and evaluation in their areas of specialization and (b) publications (i.e., books or articles in national journals) related to program development and evaluation. Experts stated in writing that the questions reflected the purpose of the study, that the wording of the questions facilitated ease of understanding, and that the order of the questions supported optimal comfort during the interview.

The interview questions were (a) How did you feel about the program when you first started? (b) How does that compare to how you feel now? (c) How did you feel about yourself as a parent of a child with a disability when you first started the program? How did you feel about your child with a disability when you first started the program? How did you feel about your family when you first started the program? (d) How does that compare to how you feel now? (e) What were your expectations of the program and the basis of them? (f) How have they been met? (g) What aspects or components of the program are the most beneficial to your child and family? (h) What aspects or components of the program are the least beneficial to your child and family? (i) What is your opinion of the knowledge and skills of the researchers? (j) What is your opinion of the knowledge and skills of the teachers (i.e., university students)? (k) Please identify any other issues related to the quality of the program. (l) What suggestions can you offer for improving the program? (m) Do you have further comments or questions?
Procedure Concerning the On-going Program

Following is a description of the PSI program that we describe as university-directed, parent-implemented, and home-based. The clinic, at the time the data for the present study were collected, was directed by a professor of adapted physical education (the second author) and coordinated by the primary researcher. The primary researcher’s role in the PSI included scheduling the family participants, conducting the developmental pretest and posttest assessments of the children, designing and revising the individualized PSI, sharing in parent and teacher training of the interventions, and collaborating in dissemination of the study’s findings.

University practica students (juniors, seniors, master’s candidates) enrolled in adapted physical education or early intervention courses worked, as partners, with the parents of the infants and toddlers with Down syndrome served by the clinic. All students were trained by the researchers to work with the parents. Training included specific information about the family each student was assigned to work with, communication skills, positioning and handling guidelines, selection and use of adapted equipment, and implementation techniques for the exercises. The researchers observed and supervised each clinic, providing assistance as necessary to the practica students and families.

Interventions were conducted as 8-week clinical periods every fall, spring, and summer. Parents could enroll their family in as many of these interventions as they wished. Intervention focused on individual families, although at times, the children were assembled in a group for a motor activity. During the years from 1994 to 1998, from 4 to 8 families were served at any given time. Service began with pretesting of the motor skills of the infants and toddlers so that the PSI could be designed specifically for each child. All testing was conducted by the primary researcher using the Hawaii Early Learning Profile (HELP), Strands (Parks, 1992), and the Battelle Developmental Inventory (Guidubaldi, Newborg, Stock, Svinicki, & Wnek, 1988). Table 1 reveals that families had completed 1 to 8 clinical periods, \( M = 4 \).

The clinic director, project coordinator, and university practica students shared in preparing each family unit to implement the exercises that the researchers specially designed for their child. These exercises were based on assessment data collected each semester. Preparation of parents included demonstrations of the exercises and supervised hands-on practice with their infant or toddler. We gave the parents a set of written and pictorial descriptions of each exercise (see Cowden et al., 1998) and a PSI Performance Chart, which stated the specific exercises their child should perform, the frequency, and the number of sets and repetitions. Parents were encouraged to utilize resources, toys, and supplies that already existed within the home. They were also loaned the university’s equipment and were given suggestions for making homemade equipment. No more than eight exercises were prescribed for a child at one time. We asked families to ascertain that each exercise was performed four times (frequency) during the coming week and to write how often and how many times the exercises were actually performed on the PSI Performance Chart. Parents brought the PSI Performance Chart to the weekly clinics. Based on observations of the infant or toddler, parent comments, and data recorded on the chart by the parent, the clinic director and project director determined which exercises were needed for the following week and provided additional parent preparation as was needed.
The goals of the PSI were (a) empower parents to implement the PSI program in the home environment independent of the university staff; (b) meet expectations of parents that the program would improve the motor development of their children; and (c) provide a university-directed, parent-implemented, home-based program that parents would perceive as worthwhile. We recognized that the extent to which the program was worthwhile would vary according to the goals of individual parents and their perceptions in terms of achievement of goals; cost of achievement in terms of energy, time, money, and other resources; and their affectivity in regard to participation. A worthwhile program was thus defined as one perceived as effective, efficient, and affectively positive (see criteria for evaluating program).

Procedure Concerning Data Collection and Analysis

The interview protocol and the content and structure of the interview questions followed the recommendations of Coffey and Atkinson (1996), Kvale (1996), and Rubin and Rubin (1995). Both parents were interviewed to obtain a fuller perspective of the contextual dynamics that existed within each family. Parents of the same family unit were interviewed independently of one another and immediately following one another. Interviews lasted approximately 30 min.

Interviews were conducted in the participants' homes by the primary researcher. Rapport already existed between the interviewer and interviewees because they were participants in the PSI. At the beginning of each interview, the interviewer “framed” (Kvale, 1996, p. 127) the interview for the parent. First, the interviewer reminded the parent of the purpose of the interview, the need to use the tape recorder, the right to decline to answer any questions, and the right to ask questions before the tape recorder was turned on. Following the completion of the interview, the interviewer “debriefed” (Kvale, 1996, p. 127) the parent by thanking him/her for participating in the interview and noting that a transcript would be mailed within a few days for the interviewee to review.

Interviews were audiotaped. As needed, the interviewer sought additional information, asked a specific question to obtain a more precise answer to the original question, and asked interpretive questions to clarify her understanding of the interviewee’s response (Kvale, 1996). Likewise, the interviewer used silence and head nodding to allow the parent more time for thought (Glesne, 1999).

Within 4 hr of each interview, the primary researcher transcribed the audio tape and mailed the interview transcript (with a stamped return envelope) to each parent for corrections. The parent was asked to review and return the transcript within 24 to 48 hr of receiving it. By conducting these member checks, the researcher ascertained that the parents believed that the transcripts were an accurate reflection of what they said or intended to say. This supported the validity of the interviews (Guba, 1981) and maximized the active involvement of parents in the research (Mishler, 1986).

Upon receipt of the reviewed transcripts and comments, the primary researcher corrected the transcripts as requested and analyzed the data in accordance with content analysis procedures (Bordens & Abbott, 1999; Holsti, 1969; Krippendorff, 1980):

1. The initial reading of the transcripts consisted of a microanalysis (i.e., a detailed, line-by-line analysis of the words and sentences of the participants). The
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Microanalysis was further conducted in subsequent phases by using a word processor and hand tallies (Strauss & Corbin, 1998).

2. Each sentence of the interviews was analyzed and divided into units of meaning (e.g., I’m more confident, He’s more mobile). The researcher then organized the units of meaning in table format (Miles & Huberman, 1994). By inspecting the table for each interview question, the researchers could see the responses by family unit, by mother, and by father. The researchers could also determine the frequency that similar responses occurred.

3. The primary researcher studied the tables to identify the actual existence of categories (e.g., parent empowerment, child development) by marking each word, phrase, or sentence that actually addressed the question asked. The researcher then marked responses that also related to other questions.

4. The primary researcher examined the data for the depth and breadth of the responses, noting which responses occurred once or only a few times from the same or different family units and from either mothers or fathers and those responses that occurred multiple times within and across families and interventionists.

5. The similar responses were assembled in relation to the research questions that they most closely answered.

Results

Research Questions 1, 2, and 3

Answers to interview questions, analyzed in relation to the first three research questions, fell into three categories and provided evidence that parents perceived (a) themselves to be empowered to implement the PSI program in the home environment independent of the university staff; (b) their expectations about improved motor development of their children had been met; and (c) the university-directed, parent-implemented, and home-based program was worthwhile. Empowerment, for purposes of this study, was defined as “the process by which individuals gain control over their lives, a sense of power equitable to that of others, and a feeling of responsibility for self, others, and environment” (Sherrill, 1998, p. 4). In this regard, Gutierrez (1990, p. 201) stated: “Empowerment is a process of increasing personal, interpersonal, or political power so that individuals can take action to improve their lives.” Fetterman, Kaftarian, and Wandersman (1996, p. 4) explained, “A process is empowering if it helps people develop skills so they become independent problem solvers and decision makers.” We used these definitions as aids in analyzing and interpreting the answers that parents gave to interview questions.

Feelings Before the Program

In response to the question, “How did you feel about the program when you first started?” most mothers responded with such phrases as “I needed help,” “intimidated, still depressed,” “overwhelmed, thinking I couldn’t do it,” “didn’t know what to do with child and wanted to make sure he was getting the right attention,” “apprehensive/worried about what was in store,” “unsure, didn’t know exactly what it was all about . . . knew we needed something more than what we had,” “excited someone could and wanted to help,” and “I was so confused and was...
hoping this was what we needed.” These statements were interpreted as indicators that most mothers believed that they did not have the knowledge and/or other resources to provide concrete help for their children in the area of motor development (i.e., they lacked the power of feeling self-confident and in control of their lives). In essence, these mothers wanted to be helped. Two mothers (one a special education teacher) emphasized that they wanted to learn how to help themselves: “I thought we can actually do something to make our child better; we can physically do something to help our child.”

Fathers’ responses to how they felt at the beginning of the program were briefer than mothers’ and less emotional, revealing less hands-on involvement. Space does not permit detailed coverage of both parents’ responses. Interested readers should refer to Sayers (1999). Typically, the fathers made global statements about how they hoped the program would help their child rather than describing their emotions: “Positive, because it would help my child,” “good, because new resources, a start, how to do it,” and “hopeful that child would benefit.”

Feelings After the Program

When asked, “How does that compare with how you feel now?” mothers responded with such statements as “don’t feel overwhelmed at all . . . they are thorough, and I know exactly step-by-step what to do;” “empowered because I can now do something about my child’s disability;” “comforting feeling when someone helps you help your child be all that he can be;” and “great about the accomplishment . . . gotten so much direction . . . child’s more confident . . . we’re more confident.”

Fathers’ responses were typically shorter and focused on a judgment about the child’s progress rather than personal feelings: “saw improvement . . . she’s practically a normal child now, physical-wise,” “saw child making progress;” and “it did the child good by going.”

Questions Used to Check Trustworthiness of Data

To check consistency in parents’ descriptions of their feelings, the same content was sought with questions worded differently and asking for more detail. Parents were asked, “When you started the program, how did you feel as a parent of a child with a disability?” “How did you feel about your child with a disability?” and “How did you feel about your family?” Then parents were asked, “How do you feel now?” Table 2 presents illustrative responses from the mothers. Fathers’ responses were similar, and because of space limitations, we chose not to include them here.

In general, Table 2 indicates that mothers’ descriptions of themselves at the beginning of the program were similar to statements made in response to earlier interview questions: overwhelmed, afraid, scared, unsure, helpless. Feelings about the child centered mostly on love, desire to help, worry, concern, and fear. Feelings about family ranged from love and appreciation of support to desire for husband and wife to do things together to isolation, “feeling like the child was all mine to deal with.”

Descriptions of feelings after participation in the program included the phrase, “more confident” more often than any other phrase. Mothers also reported that they saw themselves as “more competent,” “more comfortable,” and “more able.” Feelings about the child centered on actions: “enriched our lives . . . taught siblings
### Table 2  Feelings Reported By Mothers Before and After Participation in the Program (Illustrative)

<table>
<thead>
<tr>
<th>Feelings Before</th>
<th>Feelings After</th>
</tr>
</thead>
<tbody>
<tr>
<td>Still overwhelmed; frightened of the disability; stereotypes; isolated; like child was all mine to deal with.</td>
<td>I feel very competent now; our family is more involved with our child and accept him, help him.</td>
</tr>
<tr>
<td>Afraid that I would be unable to provide the help my child needed; happy to have my child; fortunate to have a very loving and supportive family.</td>
<td>I’m more comfortable now; I’m more confident now; child has surpassed all my expectations and enriched our lives; child has taught siblings to be more caring and considerate.</td>
</tr>
<tr>
<td>Scared to death; scared I wouldn’t know what to do; loved child to death; family was very supportive.</td>
<td>I’m more confident, more sure; I know I can handle it; I can figure it out; I can get help.</td>
</tr>
<tr>
<td>Unsure of self; unsure if I was doing everything I needed to for child; worried for her; concerned about her but starting to realize what a joy she was and really be happy; thought it would be something my husband and I could do together.</td>
<td>After program, I felt more confident about myself, my child, and my child’s future; my husband and sibling helped but I was the primary interventionist.</td>
</tr>
<tr>
<td>Helpless; we had nothing to do or use when we left therapy or clinics; we weren’t participating in any of her programs; wanted to help her; she was helpless; we needed something but didn’t know what; we all needed something we could work on together for our child with Down syndrome; we felt limited in helping her.</td>
<td>We feel wonderful because no more confusion; program gave us a sense of family participation to help child; saw child’s mind/interaction click; saw child develop sense of confidence; know child will be fine if working on something; endless work and exercises to do.</td>
</tr>
<tr>
<td>Scared; nervous; could I teach him? felt he was strong; he could do anything; our responsibility to teach him; felt that if we helped him he would adjust and it would help him; family was very supportive.</td>
<td>Proud of time and effort we (husband and I) gave to child; we’re lucky he is strong; he’s willing to try new things; our hard work has paid off; I don’t have any regrets; I’m always searching for more information; I’m hard on myself if I can’t teach him something right away; I’ve grown to have more patience; I know it will come in time - that you can’t push him to do anything.</td>
</tr>
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</table>
to be more caring and considerate” and “saw child’s mind click.” Feelings about the family generally indicated greater involvement with the child, an increased sense of family, and pride in their family’s efforts and achievements.

Expectations Before and After the Program

Parents were asked, “What were your expectations of the program?” and “How have these expectations been met or not met?” Three mothers indicated, “No definite expectations.” They were simply enrolling in the program in hopes that it would somehow help something. Most other parents expected “child to get strong . . . develop muscle tone,” “to increase child’s muscle tone and reach motor milestones like a typical child,” “to make him strong and keep him strong,” and “help me to help child get stronger and reach developmental milestones sooner.” One mother’s response was different from that of others because it was filled with doubt: “didn’t really know if it was going to make a difference . . . doubted if it would really work . . . doubted that we could really do it.”

Of the 11 mothers, 8 said that expectations had been met. The other 3 mothers said, “didn’t have any expectations and didn’t think of expectations, just did it.” The mother who initially expressed so much doubt responded: “met because we saw improvement, especially with legs, gait, and muscle tone.” Some parents added concerns about the time it took to meet these expectations: “didn’t realize how time consuming it would be . . . we taught housekeeper to do some of the exercises.” Others expressed additional values not included in their original statement of expectations: “discovered other similar kids with the same needs . . . discovered people willing to help . . . good to see people involved.”

Perceptions of Most and Least Beneficial Aspects of Program

Responses concerning the most beneficial aspects of the program were varied. The following categories of benefits were described in many ways: “having a well qualified teacher,” “teacher made me believe I could do these exercises on my own,” “the in-home instruction was helpful,” “ya’ll were always there to demonstrate the exercises and answer our questions,” “provided us with a sense of direction . . . gave us something we could do,” “PSI Performance Chart accountability . . . hard to do at the time, worth it because see progress, note reminders of what works,” “the family participating together . . . gives us more quality time,” “having constant contact weekly by phone or in person . . . me being reinforced,” “showing us how to incorporate exercises into daily life . . . therefore natural, ongoing,” and “support in knowing there are other children with Down syndrome out there.” In particular, many of the responses focused on program strategies that contributed to feelings of personal competence in helping the infant or toddler achieve motor goals. One parent summarized: “me getting more hands-on; it empowered me, I felt more confident and more involved and more in charge of what was going to happen; I had a little more control.”

With regard to least beneficial aspects of the program, 4 of the 11 mothers could not think of anything. Others indicated “finding time to do it,” “long travel time to the program,” “teacher needed to be more aggressive, energetic, persistent,” “need more small group activities at end of period for social interaction,” “child didn’t like to do exercises,” and “time spent on upper body exercises because we were trying to improve gait.”
Fathers tended to say the same things as mothers, but fathers sometimes were more direct and more concerned about sacrifices and difficulties. Illustrative of this were these statements: “You make sacrifices; it’s rough, sometimes hard to come on Saturday because you can’t sleep in but you know the benefits are coming;” “child got frustrated with hard exercises that she couldn’t do,” and “wondered why we were doing things that kid already did but figured repetition never hurts.” Many of the fathers’ criticisms focused on their desire for take-home exercises to be more individualized; it is possible that fathers did not understand the purpose of exercises or correctly evaluate the degree of individualization. Some fathers did not seem to realize that each week’s exercises were based on assessment of the child. Those outcomes could be a result of the fathers individually assuming supporting roles, although they were not asked to participate to any lesser extent than mothers.

Opinions About Researchers and Teachers

In this study, researchers referred to the program director and the program coordinator, whereas teachers referred to the university students who were gaining practicum experience through work with parents. All of the parents made positive comments regarding the researchers’ knowledge of motor development. Many parents made positive comments about the design of the intervention. Some parents commented that the researchers “made it a point to keep us informed,” “explained the rationale, benefits, and mechanics of each exercise,” and “were very encouraging to us.” Some parents acknowledged their observations of the teachers’ learning and growth throughout the semester. Most all of the parents felt that the teachers were “eager to work with us,” and “wonderful with our child.”

Other Issues Related to Quality of Program

Parents used the request to “please identify any other issues related to the quality of the program” to comment on both strengths and weaknesses. Some strengths emphasized were “child’s overall development improved greatly,” “very person-centered, not a generic program,” “didn’t have to have high tech stuff . . . useful to develop own homemade equipment,” and “everything was clear to us and I was very comfortable calling you.” Some weaknesses mentioned were “improve students’ organization and preparation,” “classes were disorganized at beginning of semester but got better,” “would be better if university students were finished with classes and not still learning,” and “the recommendations of PT and APE do not always jive and that was confusing for me.”

Suggestions for Improving the Program

Responses to “What suggestions can you offer for improving the program?” centered on time elements, individual needs, and improvement of instructional materials. With regard to time, parents said “have it year-round,” “increase number of weeks in each session and number of sessions per week,” and “be more organized so don’t waste time at beginning of semesters.” With regard to individual needs, illustrative suggestions were “keep my child confined . . . block off his area where he doesn’t have all-round stimulation,” “think of way to involve father more,” and “more coordination between PT and UNO/APE.” With regard to improving quality of materials, suggestions included “have better pictures than stick figures,”
“videotape UNO sessions as a learning tool for exercises, also we would be able to see the progression more from week to week,” and “continue with simple handouts . . . really helped us stay on track instead of books and stuff.” With the exception of comments about more time, no suggestion was made by more than one person. Responses related to the quality of the program and suggestions for improving the program were used to develop guidelines for future early intervention programs, which are discussed below.

Research Question 4

Research Question 4 sought parents’ recommendations about parental involvement in the delivery of services to infants and toddlers with disabilities. Three general criteria were used in analyzing each recommendation: (a) the practicality of implementing the recommendation through the PSI program, (b) the practicality of implementing the recommendation through a program located elsewhere that implemented the PSI approach, and (c) the likely benefit of the recommendation to all children and families enrolled in an infant and toddler adapted physical education program. We used recommendations that met these criteria to develop guidelines for early intervention programs, which are given next.

Guidelines for Future Early Intervention Programs

The second part of this study’s purpose was to analyze parents’ perceptions as a means for deriving guidelines for developing and evaluating future early intervention programs. This analysis resulted in identification of seven guidelines already in practice and four new guidelines. Guidelines already in place and evaluated as good by parents were (a) active participation by the child’s parents (or primary caregivers) during the intervention, (b) parent preparation that consists of multiple methods for learning, (c) home-based implementation of the intervention, (d) checkout equipment available for the parents’ use, (e) parents given advice on how to adapt their home environment or make home-made equipment, (f) program personnel practice techniques of good communication, and (g) program personnel remain available to communicate with the parents before, during, and after each university-based session.

New guidelines for PSI programs were (a) parents should be assisted in involving all family members in the intervention if this is their desire, (b) individual attention should be balanced with interaction with other families, (c) conscientious efforts should be directed toward organization of all aspects of the program, and (d) program administrators should take initiative to engage in open communication and collaboration with all early intervention service providers used by each family.

Discussion

The purpose of the study was to analyze parents’ perceptions of their participation in a university-directed, parent-implemented, home-based pediatric strength intervention program as (a) one approach to evaluating the effectiveness of a program conducted over a 4-year period with families of infants and toddlers with Down syndrome and (b) a means of deriving guidelines for future early intervention programs. The open-ended interview questions led to the participants giving a variety
of responses. The fact that a participant may not have mentioned something that another participant mentioned did not denote their agreement or disagreement with the statement. It simply underscored the variability among individual needs and family situations.

In relation to Research Question 1, the participants' responses consistently revealed perceptions of being empowered through active involvement in the PSI with their child and through seeing and interacting with other children and parents. The parents related that they no longer felt hopeless, powerless, or limited but that they had a sense of direction as to what they can do to help their child. They expressed increased feelings of control and confidence after participating in the PSI. Thus, the parents related a positive change in their emotional development through their participation in the PSI. Prior research in early intervention has also demonstrated that parents’ acquisition of information and problem-solving skills contributes to feelings of empowerment (Thompson et al., 1997). In this regard, Thompson (p. 100) suggested that “A key measure of program success centers on whether implementation of Part H (i.e., early intervention) influenced the level of empowerment among participants.”

In Relation to Research Question 2, many parents indicated that their primary reason for enrolling in the program was an anticipation of improvement in their child’s motor development. All of the parents gave examples of how their child’s motor development improved during participation in the PSI. Also, some of the parents spoke of the benefits to the child’s cognitive and social development. The parents seemed to become more committed to the program at the point in which they “saw results” or determined that the program made a difference for their child. Almost half of the parents indicated that they needed more information in order to help their child and that they saw this program as a way to gain some of that information. In relation to Research Question 3, the interview data indicated that the participants perceived the program as worthwhile. Data related to this research question were analyzed according to our previously given definitions of effectiveness, efficiency, and affectiveness. The affectiveness of the program was indicated by parents’ increased feelings of empowerment. The effectiveness of the program was indicated by the parents’ observations of improvements in their children’s motor development and their increased knowledge of how to work with their child.

Efficiency was indicated by the parents’ approval of the overall structure of the program. The participants of the PSI program strongly liked the home-based aspect of the program. This supports the work of Mahoney and Filer (1996), who concluded that services with home-based components were favored more by parents than programs with only center-based services. The home-based approach is congruent with federal early intervention legislation and recommendations from professional organizations.

Data from the parent interviews indicate the extent to which parents have invested much time and energy in implementing the home-based PSI. Some of the parents sought assistance from others in implementing the program. Those parents not only trained their spouses but also trained other caregivers to assist with implementing their children’s PSI. This finding supports previous research regarding parent training. Bruder and Bricker (1985) showed that parents could be effectively trained to train other parents to teach their children.

Some participants expressed reservations about the program. Some participants believed that more collaboration and communication were needed between
the PSI researchers and other early interventionists. A few participants believed that the organization of the PSI sessions held at the university needed to be better organized, especially at the beginning of each PSI period.

In relation to Research Question 4, parents were able to offer suggestions for improving the program. These suggestions recognized some aspects of the program that were functioning well and should be continued in order to continue with the success of the program. Other suggestions were given for aspects of the program that could be changed or added to improve the organization and delivery of PSI services.

We analyzed the impact of two factors that affected the participants’ responses. The first factor pertained to the families’ enrollment in other early intervention programs (e.g., PT, speech) and the subsequent enrollment of some families in other motor development programs offered through the university. Participation in other programs, in addition to the PSI, appeared to enrich parents’ perspectives. By examining the interview responses, we found that these parents had a broader basis for evaluating the quality of the PSI program. Comparison of different intervention programs appeared to be beneficial because it increased the depth of the responses and the appropriateness of the participants’ recommendations.

The second factor that may have affected some participants’ responses was the length of time since the participants’ participation in the PSI. Of the 11 families, 4 had not participated in the PSI for 3 or more years. The average participant had not participated in the PSI for 1 year. Research indicates that the structure of discourse affects the structure of recall (Barclay & Smith, 1992; Bruner & Feldman, 1996; Hirst & Manier, 1996). Recall accuracy was addressed in this study through the use of multiple questions that sought the same content. Another method to promote recall accuracy was the use of open-ended question and the allowance of the time needed for participants to complete their responses before the next question was asked. In addition, most of the questions sought the participants’ general recall, not specific recall. However, we must acknowledge: “Accuracy is often impossible to decide. It assumes a neutral observer who knows what really happened in a way that is correct for all other observers” (Rubin, 1998, p. 7).

This study relied on the participant’s autobiographical memory, which has been defined as conscious recall or episodic memory (Tulving, 1972, 1983). Further, “It is accompanied by a sense of reliving, a sense that the remembered event actually occurred to you at a specific place and time” (Rubin, 1998, p. 49). Most contemporary researchers contend that memory is constructed (Conway, 1990; Garry, Loftus, & Brown, 1994) and recall is affected by conditions at the time of construction (Christianson & Safer, 1996). There are inconsistent laboratory data on the extent of memory as it relates to mode of communication for relating memories (i.e., written or spoken; Bekerian & Dennett, 1997; Morton, Hammersley, & Bekerian, 1985). Edwards and Middleton (1986) suggested that memory is influenced by communicative conventions rather than an individual’s cognition or memory properties. Emotions can also influence memory as “Individuals are more likely to remember emotion-arousing events than neutral, everyday events” (Christianson & Safer, 1996, p. 219), including events of one’s daily activities. However, whenever individuals are asked to evaluate past experiences and conditions, it is possible that their memory will be a limiting factor. Twenty-one of our 22 participants were able to give specific answers related to the question that asked what aspects or components of the program were most beneficial. Two of our 22 participants said that because they were supporting interventionists, they could not
answer the question related to identifying aspects or components of the program that were least beneficial to them. Also, 21 of the 22 participants were able to give specific answers to each of the first four questions related to their feelings before and after participation in the program; the one who could not was a supporting interventionist. One parent of a family unit who participated in subsequent university clinics could not answer a particular question because of having trouble remembering the situation. Recognizing and acknowledging the limitations of a study is an important element in the trustworthiness of interview findings. Other limitations were (a) parents may have been reluctant to offer negative criticism in a face-to-face setting, and (b) the emotional involvement of the primary researcher may have affected parents’ reactions and subsequent interpretation of interview data. These limitations, however, are present in all interactions between human beings in helper and helpee roles. Conducting the interviews in the participants’ homes presented elements that the interviewer could not control in terms of noise level, interruptions, and the interviewees’ sole attention to the interview. In addition, the interviewer could not control the atmosphere and environment of each home and the influence those atmospheres and environments had on the participants when they were interviewed. Holding the interviews in the interviewees’ home, however, may have added to their comfort.

**Conclusion**

The parents’ responses provided support for the inclusion of parents in early intervention program evaluations. Based on findings, it was concluded that the parents’ perceptions of the PSI program provided sufficient, meaningful data for evaluating the PSI program and for deriving guidelines for developing and evaluating future motor development intervention programs. Parents’ responses to interview questions indicated that the program was effective, efficient, and positive in affect. Parents perceived that goals were met; that time, energy, and money expenditures were in balance with perceived outcomes; and that feelings about the program were good.

The parents’ recommendations for improving the PSI demonstrate a deep level of commitment to the program. As suggested by Upshur (1991), asking parents for specific feedback about their service experiences may reveal critical differences and assist service planners in understanding the variability in family needs and program outcomes. The guidelines developed, based on the parents’ responses, were intended to improve our program as well as other early intervention programs. Once the guidelines for future PSI programs are implemented, we recommend that participatory action research be used to assess how the guidelines function in reality.

**References**


Acknowledgment

This article is based on the first author’s dissertation, completed at the University of New Orleans. Dr. Sayers wishes to thank the Co-Chairs of the dissertation committee: Dr. Wilma Longstreet and Dr. Jo Cowden and members of the dissertation committee: Dr. Charles Gifford, Dr. Judith Kieff, and Dr. Claudine Sherrill.