

Parental Participation in Intervention Programs for Children with Cerebral Palsy: A Review of Research

**Marjolijn Ketelaar,
Adri Vermeer,
Paul J. M. Helders, and
Harm't Hart, Utrecht
University**

Parental participation in intervention programs for children with physical disabilities has become an important issue in recent years, often emphasized by both professionals and parents. In this article, recent studies examining parental involvement in intervention programs for children with cerebral palsy are reviewed. Only a few studies were found that were explicitly designed to study the effects of parental involvement. Most of these studies reported positive results, especially regarding child-related outcomes. The effects on the parents were less clear, with positive and negative results reported. One important variable distinguishing programs with positive effects was the degree to which parents were involved in setting goals for their children's programs. Recommendations for practice and future research are given.

Parental participation in intervention programs for young children with physical disabilities has been increasingly emphasized in recent years (S. K. Campbell, 1991; Kohn, 1990). Surveys of both parents and professionals (King, King, & Rosenbaum, 1996; Milner, Bungay, Jellinek, & Hall, 1996; Rosenbaum, King, & Cadman, 1992) as well as scholarly writing (Kolobe, 1991; Peterson & Cooper, 1989) have suggested that parental participation is crucial for improving performance in children with physical disabilities.

A number of reasons have been suggested to support the inclusion of parents as participants in their children's intervention (e.g., P. H. Campbell, 1987; Levitt, 1995; Shepherd, 1995). First, children with disabilities have difficulty transferring skills learned in one context into another. Furthermore, one of the most critical requirements for motor learning to occur is practice. An effective therapy program should address both issues and allow for frequent practice of clusters of related functional skills in contexts where the skills would typically be used (McCormick & Noonan, 1984). Therefore, home-based programs of intervention that involve parents and allow for the practice of skills in everyday

situations in a natural environment should be more effective than training by a professional in a therapeutic setting. Second, it is assumed that daily home-based physical therapy provided by the parents is more efficient than physical therapy given by a therapist for a half hour once a week (P. H. Campbell, 1987). Third, it is assumed that the involvement of parents in intervention programs may improve their understanding of their children's development and capacities and may help them to develop appropriate expectations for their children's futures (Palmer et al., 1988). Finally, it is assumed that, by helping parents to acquire the skills to teach their children, parents' competence and confidence will increase, benefitting the family as a whole (Barna, Bidder, Gray, Clements, & Gardner, 1980).

Although these arguments may be accepted by many professionals, it is important that the assumptions be confirmed by thorough research. First, however, it is important to realize that although the general concepts related to the value of parent participation have been accepted for some time, specific attitudes and practices regarding the actual meaning of parental participation are continuously changing. Attitudes and beliefs regard-

Address: Marjolijn Ketelaar, Department of Educational Sciences, Faculty of Social Sciences, Utrecht University, Heidelberglaan 1, 3584 CS Utrecht, The Netherlands; e-mail: M.KETELAAR@FSW.RUU.NL

ing parental participation have evolved from very limited parental involvement (i.e., the parents' role was that of passive bystander) to the role of parents as cotherapists, whereby therapists continued to make decisions regarding treatment and parents were encouraged to carry out therapeutic activities with their children. In recent years, beliefs regarding optimal parental participation have evolved again, from parents as cotherapists to parents as equal partners with professionals in intervention programs for children with physical disabilities (Bazyk, 1989; Simeonsson & Bailey, 1990).

For this article, *parental participation* is defined broadly and refers to all forms of parental involvement in programs, except those forms in which the parent's role is one of passive recipient. Therefore, both programs in which parents are viewed as cotherapists and programs in which parents and therapists collaborate as equal partners were considered as intervention programs with parental participation.

One early intervention target population that has received considerable attention in the literature is children with cerebral palsy. The term *cerebral palsy* is a description, not a specific diagnosis, of the clinical sequelae resulting from a *nonprogressive* encephalopathy. Cerebral palsy is characterized by sensorimotor dysfunction, which has as its expression abnormal muscle tone and abnormal posture and movement (Wilson, 1991). *Nonprogressive* implies that the degree of the disorder does not change, but this does not mean that the clinical picture does not change during development or under the influence of therapy, education, and training. Early intervention, in the form of physical or occupational therapy, has been suggested to facilitate skills required for activities of daily living. Over the years, many systems of treatment for cerebral palsy—such as Neurodevelopmental Treatment (NDT), Vojta, and Conductive Education—have been developed, most of them emphasizing the role of parents in the treatment of their children (e. g., Scrutton, 1984).

Because attitudes and beliefs regarding parental participation have been continuously changing and because the need of parental involvement in the treatment of children with cerebral palsy is being more and more emphasized (e.g., Levitt, 1995; Shepherd, 1995), it is important to review recent research on this subject. In 1985, Parette and Hourcade presented a review of the literature published between 1960 and 1982, concerning parental involvement in intervention programs for children with cerebral palsy. They selected investigations in which there was "at least minimal reference to parental involvement." They found a total of only six studies and concluded that there was a relative paucity of data-based research supporting the presumed advantages of parental participation.

The purpose of this article is to review *recent* studies examining parental involvement in intervention pro-

grams for children with cerebral palsy. Because of the diversity in programs, the heterogeneity of the research questions, and the range of variables studied, we have chosen not to conduct a meta-analysis. A variety of programs are contrasted with regard to the content, the role of parents, and the child and family-related outcomes. This comparative review may facilitate an understanding of factors relating to the effectiveness of early intervention programs for children with cerebral palsy in which parents are involved.

METHOD

The present review is based on studies published from 1980 to 1996. Studies were selected on the basis of a literature search with *Index Medicus* (Medline) and *Psychological Abstracts* (PsychLIT) using the key words "cerebral palsy," "parent(s) or family or home," and "intervention or treatment or management or therapy." First a selection of studies was made on the basis of the abstracts. A number of studies focused on children with different kinds of disabilities. All studies in which at least one group of children with cerebral palsy under age 5 years was involved were selected. Only studies in which there was reference to parental participation in intervention programs for their children with cerebral palsy were included. Studies in which the effects of a specific program were examined and in which parents were involved were examined according to the following criteria:

1. Study sample: (a) total number of children in the study, (b) inclusion of a control group, (c) number of children with cerebral palsy participating in the study, and (d) age of children.
2. Program features: (a) content, (b) form, (c) intensity, and (d) duration of the program.
3. Role of parents: (a) extent and (b) nature of the involvement of the parents in the program.
4. Dependent variables and instruments: (a) reported child- and parent-related outcomes and (b) measurement of these variables.
5. Methodology: (a) design of the study and (b) evaluation of the results.
6. Results: main results of the study.

RESULTS

The literature search yielded 16 articles published from 1980 to 1996 in which there was reference to parental participation in the intervention program for children

with cerebral palsy. The 16 papers cover 13 different studies; some studies were reported in more than one article. The key features of each study—including the sample, a short description of the program, the role of parents in the program, the dependent variables and the instruments used, the method, and the most important results—are provided in Table 1.

Of the 13 studies, only 7 (Barna et al., 1980; Gross, Eudy, & Drabman, 1982; Hanzlik, 1989; Hinojosa, 1990; Sarimski & Hoffmann, 1993; Short, Schkade, & Herring, 1989; Von Wendt, Ekenberg, Dagens, & Janlert, 1984) were explicitly designed to study the effects of parental involvement. In the other studies, parents were involved in the program, but this involvement was not an independent variable. Because the seven studies that manipulated parental involvement in their design are most important to the purpose of this article, they are described in most detail.

Studies Examining the Effects of Parental Involvement

Three studies included direct comparison between groups that differed in the degree of parental participation (Hanzlik, 1989; Sarimski & Hoffmann, 1993; Short et al., 1989). In each of these studies both effects on child outcomes and effects on parents were examined.

Hanzlik (1989) found that an "interaction intervention," which was focused on decreasing the mother's directiveness and constant physical contact and on increasing the infant's independent behavior, was successful in modifying maternal and infant behavior. Twenty mothers of infants with cerebral palsy were randomly assigned to either the experimental or the control group. Mothers in the experimental group received the interaction intervention. Mothers in the control group received instructions focusing on facilitating normal muscle tone and developmentally appropriate posture and movement patterns (NDT-based techniques). It was found that mothers in the experimental group engaged in less directive physical guidance and physical contact, and more positive initiations, responses and face-to-face than the mothers in the control group. Moreover, infants in the experimental group were more responsive to their mothers than infants in the control group. The described changes in both maternal and infant behavior are thought to be important for the child's development of independence (Hanzlik, 1989).

Sarimski and Hoffmann (1993) found that mothers who were involved in the therapy were more overprotective toward their children, but did not consider themselves to be more burdened and did not consider their children to be more difficult than mothers who were not conducting therapy. However, these findings are difficult to interpret because of the composition of the two

groups. The first group consisted of 25 mothers of children with cerebral palsy who were doing intensive physical therapy with their children. The specific handling techniques, according to the principles of Vojta and provoking specific movement patterns, had to be performed three times per day. The second group consisted of 25 mothers of children with mental retardation "who were not under the stress of conducting therapy" (p. 109). Thus, the groups differed in the extent of their involvement in therapy as well as in the diagnoses of the children. Therefore, the differences found between the two groups cannot be explained only by the level of involvement. In fact, it is more likely that differences could be explained by the specific problems of the children.

Short et al. (1989) found that therapists working with parents accomplished the goals of therapy in a shorter time period than those working only with the children. The effectiveness of a gait training intervention was studied using two groups of nonambulatory children with different physical disabilities. The method for assigning children to groups was not reported. In the first group, each child's mother was available at all training times (5 days, for about 4 hours per day). Except for availability, the role of the mothers in the training program was not described. In the second group, parents were not involved. The children in the first group achieved their walking skills more quickly than those who were trained without parental involvement. In addition, some of the parents in the first group noted that the greater involvement increased their confidence and that they believed they had learned better ways of coping with their children's resistant behaviors.

In the remaining four studies designed to examine the effects of parental involvement, no direct comparisons were made between groups that differed in the degree of parental participation. As distinct from the previously described studies, these four studies involved a single group that participated in a program. In two studies only effects on the children were studied (Barna et al., 1980; Gross et al., 1982), and in the other two studies only parental perceptions of their involvement were studied (Hinojosa, 1990; Von Wendt et al., 1984).

Barna et al. (1980) investigated gains in mental age of children with different disabilities after training of their parents based on the Portage Project. An important feature of this program was that parents were highly involved in all stages of the program, such as problem-definition, goal-setting, and evaluation. Parents were trained to teach their children certain (not described) skills, so "the child is being taught in his or her natural environment and by the people who are able to provide the greatest continuity of care" (p. 157). Positive effects were found for all children, but there were large differences between the groups (e.g., children with Down syndrome, children with visual disabilities, children with

TABLE 1. Reviewed Studies

Study	Sample	Program	Parents' role	Measures	Method	Results
Barna et al. (1980)	Children with different disabilities, all with a developmental delay; Ntot = 35 (Ncp = 4); Age: 3-48M	Parent training based on Portage Project: Weekly home visits from a home advisor (varying between 5 and 25 M)	Parents as teachers of their children	Child: <ul style="list-style-type: none"> Mental age (Griffiths Developmental Scales) 	Design: Time series; assessments before, during, and immediately after training Evaluation: Comparing gain in mental age before training with gain in mental age after training (no statistical analyses)	Wide differences in rates of progress for different medical groups: Children with cerebral palsy developed at the slowest rate.
Gross et al. (1982)	Children with cerebral palsy; Ntot = Ncp = 3; Age: 2.9-3.8 Y	Parent training: Parents were trained to develop appropriate movement of elbow joint of their child, using modeling and fading techniques (one session)	Parent had to apply the learned procedure 10 minutes each day	Child: <ul style="list-style-type: none"> Elbow joint angle while reaching for an object (goniometer) Subjective ratings of improvement in reaching and grasping (questionnaire, completed by therapist) 	Design: Multiple-baseline across-subjects design Evaluation: Description of increases in arm extension (no statistical analyses)	On baseline, no gains in range of motion were observed. When parents were incorporated, range of motion of the target arm increased.
Hanzlik (1989)	Children with cerebral palsy; Ntot = Ncp = 20; E = 10, C = 10; Age: 8-32 M	E: Mothers received 1 hour of instruction to improve mother-child interaction while holding and positioning the child C: One hour of NDT-based occupational therapy; mothers were taught one of the treatment techniques	E & C: Mothers were expected to put the instructed strategies into practice for 2 weeks	Child/mother: <ul style="list-style-type: none"> Mother-child interaction (rating of video-recordings) 	Design: Pretest-posttest control group design Evaluation: Group comparisons using a two-factor (treatment \times time) repeated measures analysis of variance with repeated measures on the second factor	The instruction of the E group was significantly more successful in modifying maternal and infant behavior than was the instruction of the C group.
Hinojosa (1990); Hinojosa & Anderson (1991)	Children with cerebral palsy; Ntot = Ncp = 8; Age: 2-5 Y	No uniform program; home program specified and designed by the individual occupational and/or physical therapist of the child	Mothers were expected to implement the program in daily life	Mother: <ul style="list-style-type: none"> Experience with program (interview) 	Design: One-shot case Evaluation: Qualitative analysis of interviews	Mothers selected only some activities the therapist suggested. The activities they selected were enjoyable for the child and not stressful for the mother, or the family.

(table continues)

(Table 1 continued)

Study	Sample	Program	Parents' role	Measures	Method	Results
Law et al. (1991); Law & King (1993)	Children with cerebral palsy; Ntot = Ncp = 72; Age: 1 1/2-8 Y	Four 6-month interventions: 1. Regular NDT (1-4 times a month plus a 15-minute program at home 3 times per week) 2. Regular NDT plus casting (at least 4 hours per day) 3. Intensive NDT (45 minutes twice weekly plus a 30-minute daily program at home) 4. Intensive NDT plus casting (at least 4 hours per day)	Parents had to carry out therapy activities	<p>Child:</p> <ul style="list-style-type: none"> Hand function (Peabody Fine Motor Scales) Quality of upper-extremity movement (QUEST) Range of motion at wrist (goniometer) <p>Parents:</p> <ul style="list-style-type: none"> Compliance (questionnaire and logbook) 	<p>Design: Two-by-two factorial design</p> <p>Evaluation:</p> <ul style="list-style-type: none"> Comparing groups on changes from baseline using analysis of variance with multiple comparisons Multiple regression analysis to evaluate the contribution of parent compliance 	<p>After 6 months, casting led to increased quality of movement and increased wrist extension. There was no effect on hand function. After 9 months, the changes decreased. There were no benefits from intensive therapy alone. Gain in hand function was related to compliance of parents.</p>
Mayo (1981)	Children with delayed motor development; Ntot = 18 (Ncp = 3); E = 9, C = 9; Age: 3-31 M	Mothers were given prescriptions and demonstrations of the (not described) program. At the last therapist contact (E: at home, C: at department), mothers received lists of activities	E & C: Mothers were expected to carry out prescribed daily activities for 1 month	<p>Child:</p> <ul style="list-style-type: none"> Developmental age divided by chronological age (chart by Milani-Comparetti & Gidoni) <p>Mother:</p> <ul style="list-style-type: none"> Compliance (remaining treatment supplies) 	<p>Design: Pretest-posttest control group design</p> <p>Evaluation:</p> <ul style="list-style-type: none"> Comparing pretest-posttest changes of developmental quotient between groups using a <i>t</i> test Comparing compliance of both groups using an analysis of variance 	<p>The development level of children in the E group increased more than in the C group. No significant difference in compliance between groups.</p>
Mayo (1991)	Children with suspected cerebral palsy; Ntot = Ncp = 29; E = 17, C = 12; Age: 4-18 M	Monthly (C group) and weekly (E group) NDT during 6 months, both including an individually tailored home program written out in a booklet and consisting of suggestions for positioning, handling, and stimulation	E & C: Parents were expected to carry out the home program	<p>Child:</p> <ul style="list-style-type: none"> Primitive reflexes (Primitive Reflex Profile) Postural reactions (Bobath & Bobath) Gross motor ability (Wolanski Gross Motor Evaluation) Fine motor skills (Gesell and Amaruda's Developmental Diagnosis) Mental development (Bayley Scale) Abnormal movement (sds) Activities of daily living (sds) 	<p>Design: Pretest-posttest control group design</p> <p>Evaluation: Regression analysis with change in motor development (summation of the seven scores of the seven instruments as the regressor variable, and regimen as the predictor variable)</p>	<p>The change in motor development for the infants in the E group was larger than for the infants in the C group.</p>

(table continues)

(Table 1 *Continued*)

Study	Sample	Program	Parents' role	Measures	Method	Results
Muir & Milan (1982)	Children with developmental delays; Ntot = 3 (Ncp = 2); Age: 2-2 1/2 Y	Parent training: Mothers were taught how to teach their children specific language skills; mothers were rewarded (earned lottery tickets) for progress made by their children	Mothers had to work with their children on specified task for 4 to 11 months	Child: <ul style="list-style-type: none"> • Performance of language skills (SDs) 	Design: Single-Case ABAB reversal design Evaluation: Comparing gain in language skills after a "lottery phase" with gain in language skills after a "non-lottery phase" (no statistical analyses)	In the "lottery phases" there were large improvements in the child's performance of defined language skills; in the baseline phases there was minimal progress.
Palmer et al. (1988); Palmer et al. (1990)	Children with cerebral palsy; Ntot = Ncp = 48; E = 23, C = 25; Age: 12-19 M	E: 6 months infant stimulation (focused on broad range of developmental domains) plus 6 months NDT C: 12 months NDT E & C: Parents were trained in the administration of the program, which was structured around checklists and specific behavioral objectives	E & C: Parents were expected to administer the program daily at home. Goals and procedures were always reviewed with parents at the biweekly sessions.	Child: <ul style="list-style-type: none"> • Motor development (Bayley Scales) • Mental development (Bayley Scales) • Social development (Vineland Social Maturity Scale) • Motor skill milestones (Parental report) • Spontaneous and reactive behavior (Carey Infant Temperament Q) Parent: <ul style="list-style-type: none"> • Characteristics of parenting and home environment (Home Observation for Measurement of the Environment) • Acceptance, overprotection, overindulgence, and rejection (Roth Mother-Child Relationship) 	Design: Pretest-Posttest control design Evaluation: Comparing changes from baseline of both groups using chi-square, Fisher's exact, Mann-Whitney, and <i>t</i> tests	After 6 months infants in the C group had a lower mean motor quotient and a lower mean mental quotient than those in the E group and were less likely to walk. These differences (except mental quotient) persisted after 12 months. No differences between groups on measures of home environment, parenting, mother-child relationship, or infant temperament.
Paretto, Holder, & Sears (1984)	Children with cerebral palsy or motor delay; Ntot = 10 (Ncp = ?); Age: 5-24 M	6 months NDT	Parents were expected to implement management strategies in daily life	Child: <ul style="list-style-type: none"> • Psychomotor and mental development (Bayley Scales) Parents: <ul style="list-style-type: none"> • Degree of Involvement (Degree of Involvement Instrument) • Parental hours of participation (not reported how these data were collected) 	Design: One group pretest-posttest design Evaluation: Correlating variable using Kendall's tau	Motor gains were correlated with parental hours of participation, degree of involvement of parents, and age of the child.

(table continues)

(table 1 continued)

Study	Sample	Program	Parents' role	Measures	Method	Results
Sarimski & Hoffmann (1993)	Children with cerebral palsy (CP) and children with mental retardation (MR); Ntot = 50 (Ncp = 25); Age: 1-6 Y	CP: Physical therapy, treatment according to Vojta MR: No physical therapy	CP: Mothers were doing daily intensive physical therapy MR: Mothers were not conducting therapy	Child: <ul style="list-style-type: none"> • Temperament (Infant Characteristics Questionnaire) • Attitude toward child (Questionnaire) • Coping with problems (Questionnaires) 	Design: Static-group comparison Evaluation: Comparison of two groups on questionnaires using <i>t</i> test	Mothers doing therapy (CP group) tried to compensate for their children's stress by being overprotective.
Short, Schkade, & Herring (1989)	Children with different physical disabilities; Ntot = 46 (Ncp = 19); E = 23, C = 23; Age 1 1/2-4 Y	5-16 days gait training in rehabilitation setting E: Mother was involved in the training C: No involvement of parents	E: Mother was available at all training times; no specific instructions for daily life	Child: <ul style="list-style-type: none"> • Efficiency index (distance walked in 10 minutes at discharge, divided by the number of days in training) Mother: <ul style="list-style-type: none"> • Affective response to training (Questionnaire) 	Design: Pretest-posttest control group design Evaluation: Both groups were compared on the efficiency index; statistical method not reported, <i>p</i> values are reported	The children paired with parents achieved their walking skills more quickly than those children trained alone.
Von Wendt, Ekenberg, Dags, & Janlert (1984)	Children with different motor disabilities; Ntot = 49 (Ncp = 28); Age: 0-6 Y	Parents received instructions following the principles of Bobath and Vojta	Parents were responsible for daily treatment	Parent: <ul style="list-style-type: none"> • Perception of disability of the child (Questionnaire) • Problems with performing the therapy (Questionnaire) 	Design: One-shot case Evaluation: Description of answers on questionnaires (no statistical analyses)	Parents were not overstrained by their high degree of involvement, as long as close supervision and adequate economic and emotional support were provided.

Note. Ncp = number of children with cerebral palsy; Ntot = total number of children in study; M = months; Y = years; C = control group; E = experimental group; Age refers to all children in sample; NDT = Neurodevelopmental Treatment; sds = self-developed scale.

cerebral palsy, children with environmental deprivation, children with nonspecific developmental delays"). These results must be interpreted with care because the number and ages of children in each of the groups differed largely and the conclusions were not based on statistical analyses. The authors referred to a table with raw data, reporting "It can be seen that . . ." and "It is clear that . . ." Moreover, because there was only one baseline measurement and no control group, it is not clear which part of the effects can be attributed to the involvement of parents and which part can be attributed to developmental gains. Effects on parents and parental perceptions of their involvement were not reported.

Gross et al. (1982) found that when parents were not involved in the therapy of their children with cerebral palsy during baseline, no gains in range of motion of their children's arms were observed. But after parents were trained "to develop appropriate movement of specific joints of their child's body" (p. 324), a procedure the parents had to apply for 10 minutes daily, the range of motion of the target arm of the child increased. Parental perceptions of their involvement were not reported.

Hinojosa (1990) and Hinojosa and Anderson (1991) interviewed eight mothers of children with cerebral palsy to investigate the experiences of these mothers with the (physical and/or occupational) therapy their children were receiving and in which they were expected to participate. There was no uniform program. The programs that mothers had to implement at home were designed by the individual therapists, so the nature and extent of mothers' involvement in the program varied. The most important finding was that the programs as specified and designed by the therapists were not being implemented by any of the mothers. Mothers implemented only the activities that were enjoyable and not stressful for the child, the mother, or the family. They did activities that were practical and easy to fit into daily activities, such as playing with their children.

Von Wendt et al. (1984) used questionnaires, which revealed that parents who were trained to perform daily physical treatment of their children were not overstrained by their high degree of involvement, as long as close supervision and adequate economic and emotional support were provided. Every child received a personal training program that subsequently was revised in accordance with the child's development. The physiotherapists acted mainly as instructors and supervisors of the treatment. Except for the statement that the instructions parents received "follow the principles of Bobath and Vojta" (p. 445), the authors did not describe in detail what the nature and extent of parents' involvement was. However, they referred to the therapy in terms of "training of walking, cycling on special bicycles, crawling and rising to stand," and "contracture pro-

phylaxis" (p. 446). Effects on child outcomes were not studied.

Other Studies

Although six studies were not specifically designed to study the effects of parental involvement, they are described briefly because a number of them reported interesting findings with regard to the relationship between parental involvement in therapy and child-related outcomes. Law et al. (1991) found that parental compliance was important as a predictor variable; children whose parents felt comfortable with and were able to complete the home program made more gains in hand function (as measured with the Peabody Fine Motor Scales). Thus it was concluded that parents seemed to be important in promoting their children's development and function. Mayo (1981) also suggested that a higher degree of parental compliance might have a positive effect on the child's development. Parette, Holder, and Sears (1984) found that motor gains of the child, as assessed with the Bayley Scales of Infant Development, were correlated with parental hours of participation and their degree of involvement, as reported in a questionnaire. Muir and Milan (1982) rewarded mothers (with lottery tickets) for their children's progress in language skills. Muir and Milan found that children made large gains in the "lottery phases," but in the baseline phases they made minimal progress. Motivation of parents seemed to be an important predictor variable. Finally, Palmer et al. (1988, 1990) found differences in cognitive and motor functioning between children who received 6 months of infant stimulation followed by 6 months of NDT and children who received 12 months of NDT. In both groups, goals and procedures were reviewed with the parents and parents were expected to administer the program daily at home. The suggestion that the broader emphasis of the infant stimulation curriculum would lead to improved interactions and parents coping with their infants was not supported; group differences in parenting were not detected.

DISCUSSION

Parental participation in intervention programs for children with cerebral palsy has become an important issue (S. K. Campbell, 1991; Kohn, 1990; Lord, 1984). Although many professionals consider parental involvement to be an essential component of the program, little research has been carried out to support this. It becomes evident from this review that programs differed with regard to content, objectives, nature, degree, and duration of parental participation. Furthermore, each study selected unique combinations of child- or parent-related

outcomes, which makes direct comparisons between studies difficult. However, the studies that were explicitly designed to examine the effects of parental involvement as well as some of the other studies, showed a positive effect of parental participation on child-related outcome variables. The effects on parents themselves were less clear, as both positive and negative results were reported.

Implications for Practice

This review points to several components that distinguished programs with positive parental effects from programs with limited parental effects. One of these is the degree to which parents were involved in decision making. In the studies of Hinojosa (1990; Hinojosa & Anderson, 1991) parents implemented only some of the instructions and suggestions of the therapist in daily life. The studies indicated that parents were not able or were not motivated to participate in the way and to the extent that the therapist expected. Allen and Hudd (1987) stated that when parents are expected to carry out a prescribed curriculum, they often feel uncomfortable and may become frustrated if the child does not show progress.

Parents must not only be instructed in carrying out a therapeutic exercise regimen, but also should be helped to cope with all kinds of problems in daily life, such as feeding (Denhoff, 1981). A second important component is the degree to which parents' problem-solving skills and independence are promoted (Affleck, McGrade, McQueeney, & Allen, 1982).

An active role of parents in all phases of the program is preferable; parents must be included as integral participants. First, the program must focus on the child's and family's needs and priorities. It is important to discover what parents and children want to achieve. Levitt (1995) suggested that the therapist talk about a typical day with the child and family. They should be encouraged to tell which activities they would like to improve further and which activities are most stressful or time-consuming. Second, parents must be included in goal-setting; these goals must be directed to the needs and priorities of the child and family. This may prevent unrealistic expectations and frustrations of both parents and therapists. Third, the program must be adapted to the family's capabilities, situation, and daily schedule (and not vice versa). The family must not be bombarded with suggestions from the therapist and must be encouraged to find solutions and to think about activities they can perform in daily life (Shepherd, 1995). It is the task of the therapist to support the naturally occurring opportunities that exist at home or, for example, at school to learn and practice daily skills. Finally, parents must be given regular opportunities to evaluate and reformulate goals.

Implications for Research

In their review of the literature (1960–1982) concerning parental involvement in intervention programs for children with cerebral palsy, Parette and Hourcade (1985) found only six studies, of which two used an experimental design. A comparison of our review to that of Parette and Hourcade makes clear that, with regard to focus, content, and design, research on parental participation in intervention programs for children with cerebral palsy has not changed much in recent years. Our review found seven studies that examined the effects of parental involvement, of which only three compared groups that differed in the degree of parent participation. These studies reported positive effects of parental participation on child-related variables. However, when parents are involved it is important to look at effects on the child and the parents and to look for relationships between these outcomes (Harris, 1990). A shift in emphasis is occurring in early intervention literature, from the child's impairments to the whole child, and from the whole child to the family (Graves, 1995). Unfortunately, this shift in literature has not yet been followed in research.

Future research should focus on the effects of an active role of parents in intervention programs, designed to build upon and strengthen the abilities of families. Experimental designs should be used and the effects of the program on the children themselves as well as on their families should be measured. Coping skills of the parents, parent-child interaction, and functional outcomes, such as independence in self-care, mobility, and communication of the child, should be quantified and measured. Moreover, the interrelationship between child and family outcomes should be investigated (e.g., the relationship between parental stress and the child's progress).

Finally, long-term outcomes of programs should be evaluated. In the majority of the reviewed studies, evaluation only took place immediately after the intervention or program. Kohn (1990), for example, pointed to the positive effects of family involvement on the child's long-term performance and self-concept. In addition, interventions have been demonstrated to have powerful effects on children's later social competence or future coping skills (Guralnick, 1989). Therefore, longitudinal studies are needed to document changes and determine whether generalization and maintenance of effects has taken place.♦

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