Changes in Attitudes and Beliefs Regarding Parent Participation and Home Programs: An Update

Susan Bazyk

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Attitudes and beliefs regarding parent participation and home programs in early intervention have significantly changed over the last 30 years on the basis of public policy and the needs of families. This paper discusses traditional and current attitudes and practices regarding parent participation and home programs. These attitudes and practices have been influenced by the medical model, the Education for All Handicapped Children Act (Public Law 94–142), the Education of the Handicapped Act Amendments of 1986 (Public Law 99–457), and parental concerns. We have evolved from believing that, as occupational therapists, we are the experts who teach parents what to do with their child through parent training to believing that parents and professionals need to collaborate as equal partners in developing home activities. Six guidelines are suggested for use in developing family-centered home programs, and the application of some of these guidelines is demonstrated in a case example.

Susan Bazyk, MHS, OTR/L, is Assistant Professor, Occupational Therapy Program, Cleveland State University, Cleveland, Ohio. (Mailing address: Department of Health Sciences, Cleveland State University, 1983 East 24th Street, Penn Tower, Room 705, Cleveland, Ohio 44115)

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of their child’s intervention program. Because family members were not expected to take an active role in the child’s therapeutic program, this model encouraged parents to become dependent on health professionals. Consequently, many parents were in danger of developing a sense of helplessness about their caregiving ability (Dunst & Trivette, 1987).

Public Law 94–142: Parents as Teachers and Therapists

Within the last two decades, there has been a dramatic shift from little to extensive parent participation in a child’s intervention program. One impetus for this change was the enactment in 1975 of the Education for All Handicapped Children Act (Public Law 94–142). This law provided a legal mandate for parents to be included as an integral part of their child’s educational program and defined their participatory rights (Turnbull & Turnbull, 1982). It created new expectations for parents to be part of the decision-making process; to be planners, coordinators, and advocates for their child’s education; and to assume the role of teacher at home (Roger, 1986).

This shift in philosophy was positive in that it changed professionals’ attitudes and beliefs regarding parent participation. Professionals began to view parents as capable of assuming numerous roles, including the roles of teacher and therapist (Allen & Hudd, 1987). As a result, parent training and the development of home programs became recognized parts of most early intervention programs. Occupational therapists realized the benefits of teaching parents how to follow through with activities at home to reinforce skills learned in therapy. Typically, the therapist developed a home program to extend the child’s treatment goals beyond the therapy session.

The benefits of parent training and home programs have been recognized in the literature (Allen & Hudd, 1987). Some parents have noted that, because of their expanded role in therapy, they feel more confident and competent in their role as parents (Moxley-Haegert & Serbin, 1983). In addition, studies have indicated that parent training leads to improvements in the child’s skill acquisition (Bricker & Casuso, 1979; Roger, 1986).

Although these changes were generally positive, this helping model could be classified as a modified version of the medical model. Therapists continued to make most of the decisions regarding treatment and home programs on the basis of the child’s needs, but they realized that they were not the sole providers of intervention. Parents were also responsible for assuming the role of therapist at home.

With this medical model of helping, the compliance of parents was an issue. Parents were viewed as a homogeneous group, and they were expected to provide the same amount of treatment at home. When a parent did not follow through with prescribed activities, he or she was identified as noncompliant (Cadman, Shurvell, Davies, & Bradfield, 1984). The judging of parents on their follow-through of activities reflects a belief that therapists know best and should control what occurs at home.

Public Law 99–457: Family-Centered Parent Participation

Attitudes and beliefs regarding parent participation have been evolving over the past several years, largely because of two factors: (a) professionals listening to what parents need and (b) recent changes in public policy.

Turnbull and Turnbull (1982) were among the first parents to express concerns over the impact of Public Law 94–142 on parent participation. They felt that parents were viewed as a homogeneous group and that each parent was expected to be involved in the child’s program in the same way and to the same extent. There was no room for parents to decide how involved they wanted to be. In reality, parents are a heterogeneous group and vary in their needs, interests, and availability.

Public Law 99–457 has also affected our views of parent participation. Part H emphasizes the importance of families in facilitating the development of children with special needs (Hanft, 1988). This law represents a philosophical shift from child-centered to family-centered intervention. With child-centered care, we identified what parents should do to improve their child’s development without considering the parents’ needs or concerns. The critical difference with family-centered care is that we are guided by the needs of the entire family—the parents, the siblings, and the child with special needs.

On the basis of what parents have taught us and on the legal mandate for family-centered care in early intervention, we need to make a number of changes in our attitudes, beliefs, and actions regarding our interaction with parents and the development of home programs. Six guidelines are suggested for use in developing family-centered home programs. I will use my experiences with a family I recently worked with to demonstrate the application of several of these guidelines.

Mary and Joe are the parents of Michael, who is 4 years old, and Sarah, who is 2½ years old. Sarah was born with a severe cardiac condition. As a result, she had difficulty with oral feeding and was given supplemental tube feedings. She was referred for weekly occupational therapy in the home to work on oral feeding.
Guideline 1. The Parent as Decision Maker

The parent, as consumer, is the decision maker and the one in control. The health professional is the service provider. This belief requires us to reject the medical model of helping, in which we view ourselves as the experts in control. Instead, we must adopt a collaborative model of working with families. The goal of this model is to interact with families in ways that support them in meeting their goals and in controlling their children's health care. When parents believe that their well-being is contingent on their own behavior, they are able to develop an internal locus of control rather than an external one (Cron, Friedrich, & Greenberg, 1983). An internal locus of control acts as a coping resource for parents that may reduce stress and depression and increase their sense of competence (Friedrich, Cohen, & Wiltturner, 1988). In applying a collaborative model of helping, we accept our role as service providers for the children and their parents. We serve as consultants to the parents to help them acquire the knowledge and skills that they need to care for their children with special needs.

How do these beliefs influence what we do? By viewing parents as having the capacity to understand and manage all life events, we approach them with respect and confidence in their abilities (Dunst, Tri- vette, Davis, & Cornell, 1988). We work together with parents to identify treatment choices, and we allow them to decide what best fits their family. We accept and support their decisions, whatever they may be.

For example, 2 months before Sarah's major corrective cardiac surgery, Mary expressed a need not to be involved in her child's feeding program. She felt she did not have the energy to work on oral feeding and preferred to feed her only by tube. Mary talked about her fears of the possibility that Sarah could die during surgery. Mary wanted to enjoy this time with her daughter without being concerned about her oral feeding, which she found to be stressful. I needed to accept and support this decision. Mary suggested that Sarah's grandmother could follow up with some of the feeding activities while Mary was at work; this solution met everyone's needs.

Guideline 2. Support of Parental Role Development Versus the Role of Parent as Therapist

With the enactment of Public Law 94-142, we increasingly asked parents to perform school and therapy activities at home with their children. Although some parents noted that this improved their self-confidence regarding caring for their children, other parents voiced concerns (Lyon, 1989; Roger, 1986).

One concern was that a preoccupation with structured therapy activities at home leaves the parents little time and energy for their other roles and responsibilities. We need to acknowledge all the other roles that parents might assume, including caregiver to other children, spouse, homemaker, worker, friend, and son or daughter. Keeping all of these roles in mind can help us to be more realistic when suggesting home activities.

In addition, when the parent assumes the role of therapist, there is a danger that it may have a negative effect on parent-child interactions (Tyler, Kogan, & Turner, 1974). The parents may become frustrated with their child if progress is slow. The child, in turn, may become resentful of the parents if their time together takes on the characteristic of work (Roger, 1986).

As occupational therapists, we value occupational role development and a balance of work, play, and rest. Our interactions with families must reflect this value. First, we must value all aspects of the parents' role as parents. Part of this role involves a responsibility for their child's health care needs, but it also involves time spent in mutually enjoyable interactions, nonstructured kinds of play, and rest (Allen & Hudd, 1987; Lyon, 1989). Parents need time to enjoy being parents (Shelton, Jeppson, & Johnson, 1987). When necessary, we must serve as consultants to help parents function in this role. This consultation may involve the modeling of helpful ways of handling and positioning a child for establishing eye contact, for verbal interaction, or for play (Case-Smith, 1989). Our aim is to help parents build a repertoire of skills for successful interaction with and greater enjoyment of their child (Case-Smith, 1989). When doing this, however, we need to be careful not to assume a parental role with the child. Although it is natural to interact closely with the children with whom we work, we must avoid giving any indication that we know the child better or are closer to the child than the parents are. In addition, when referring to the children with whom we work, we must avoid using the phrase my child. Such behaviors suggest that the therapist can function as the child's parent, which can seriously undermine the parent's role.

Guideline 3. Collaborative Home Treatment Programs

Collaborative home treatment programs are developed by the parent and therapist together, not by the therapist alone. We need to consider using terminology that more closely reflects this view. The term parent training connotes a one-way interaction in which the therapist teaches the parent. Instead of using this term, we need to think and talk in terms of parent-professional collaboration. The word collabo-
Collaboration more clearly represents the parent and therapist as equal partners, each sharing unique information that is useful in the development of home activities. The parents are the specialists in knowing their child and their family. The parents know their child's favorite foods, toys, and colors, and the best times of day for various activities. There is no way that we can or should know the child as the parent does. One small piece of information about a child's food preference can change an unhappy feeding experience into a happy one. We, as therapists, have information regarding intervention activities that will enhance development and also have the experience of working with a number of children with special needs (Shelton et al., 1987). Collaboration means a two-way sharing of this information to successfully identify the best intervention activities for the child and the family.

In addition, if we value collaboration over parent training, then we need to discontinue using the term noncompliance. This term implies that the parent is at fault for not carrying out prescribed therapeutic activities at home. When using a collaborative approach to develop a home program, we do not prescribe activities for the parents. We also know that the parents are not to blame if they do not follow up with home activities. Instead, we must think in terms of the therapist, the parents, or both having misjudged the activity as a realistic one. This should not be viewed as a failure on the part of either party. Together, the therapist and parents need to go back to the drawing board and identify a better fit for home activities. It is much healthier to view this experience in a positive light, as a learning process that requires good listening, problem solving, creativity, and persistence on the part of the therapist and the parents.

Guideline 4: Differences in Collaboration With Families

The degree and type of collaboration will differ with each parent and will change as the family changes. Parents must be allowed to identify their interest in, and the degree to which they want to be involved in, their child's therapy program and home activities (AOTA, 1989). We cannot judge parents on their level of involvement in their child's therapy program. Once again, it is critical to accept and respect parents for their preferences. Some parents will not have time to perform certain therapeutic activities at home or will choose not to assume the role of therapist. Participation will also vary depending on changes within the family, for example, the birth of another child, the mother taking or leaving a job, or sickness in the family.

For example, after Sarah's surgery, Mary was financially able to reduce her work hours. Consequently, she felt more relaxed and had more time to concentrate on facilitating Sarah's oral feeding ability. After Mary indicated an interest in Sarah's feeding program, we worked together to develop strategies she could use. My input was guided by Mary's interest in initiating a feeding program at that time.

Guideline 5: Options for Parents

When developing home activities, we should identify a range of options that will fit into the family's routines. We must strive to be creative and flexible in this process. Initially, it is important to talk with the parents and identify their level of interest in following up with therapeutic activities at home (Rainforth & Salisbury, 1988). We should explore with the parents their needs and priorities regarding interaction with and care of their child. Do they have any concerns about their child's feeding, dressing, hygiene, play, and interaction with or movement within the environment? Parents are often concerned with these daily, ongoing activities (Shelton et al., 1987). Occupational therapists are in a good position to share information that addresses these needs.

After identifying the parents' interests and concerns, we should explore the family's routines and help the parents identify the best times for suggested activities (Rainforth & Salisbury, 1988). Our aim is to identify activities that can be incorporated into the family's routines easily, without adding stress or pressure to the parents.

Typically, the occupational therapist is one member of the health care team who identifies therapeutic activities to attain a certain goal. When doing this, we can identify a number of different therapeutic activities and approaches and allow the parents to choose the methods and activities with which they are most comfortable (Rainforth & Salisbury, 1988). Occupational therapists differ in the treatment methods they prefer, as do parents. This difference is often based on personality, resources in the environment, and availability. Because we have found a certain method to be successful does not mean that it is the only one that will work with each child and family. In addition, we must strive to capitalize on family-identified activities (Roger, 1986). Parents who are aware of goals and general treatment principles are often able to think of naturally occurring opportunities for therapeutic activities within their daily routine, thereby enhancing their sense of control.

Finally, we need to take time to explain to parents how and why an activity will help their child achieve a certain goal. We need to ask parents how they prefer to learn (i.e., through modeling, verbal explanations, written information, or a combination of these methods). Our view of a home program must expand beyond the typical written program of activi-
ties. Some parents will find verbal explanations and modeling to be the most effective method of developing home activities. Other parents may prefer written information and diagrams. The actual form of the home program should be based on the parents' individual preferences and learning styles.

For example, when Mary indicated an interest in working on oral feeding with Sarah, I suggested an approach based on my knowledge and experience with similar children. One approach for facilitating oral feeding in children who are tube-fed is to offer foods in a graded manner before each tube feeding. After trying this for a couple of weeks, Mary admitted that she found this approach to be too frustrating. She had a difficult time accepting small gains in the amount of food Sarah would accept and as a result would force larger amounts of food during a meal. Sarah responded by becoming upset and vomiting. This approach clearly did not work for Mary and Sarah. After spending time in thoughtful discussion, Mary, Joe, and I identified a more successful approach. Mary agreed to place food in front of Sarah during mealtime and to verbally encourage Sarah to feed herself. In a sense, this approach allowed Sarah to have control. In turn, Mary felt less frustrated when Sarah would not eat. Gradually, over a period of 8 months, Sarah progressed from drinking liquids to eating solid foods.

Guideline 6: Consideration of the Child's Needs

We must continue to consider the child's needs in terms of occupational role development as well as skill development. We must view the child as a member of a family, not as a separate entity. As occupational therapists, we are quite comfortable identifying the needs of a child in terms of development in motor, sensory, cognitive, social, and self-help skills. However, if our entire focus is on skill attainment, we may fail to identify what the child needs to function in age-appropriate occupational roles. A primary occupational role for an infant is as a player. The infant needs more than skill to function in this role; he or she needs to be in an environment that fosters play. In therapy sessions, we need to model our value of play by spending time facilitating play development rather than concentrating on gross motor activities that resemble exercises. In addition, we can recommend that developmentally appropriate toys be available in the child's environment. We can also make suggestions for gifts when parents are unsure of the kinds of toys to buy.

Another of the child's roles is that of family member—son or daughter, brother or sister. In this role, the child needs to be accepted and loved by all of the family members. If we encourage parents to be overly focused on their child's developmental gains or on their child's weaknesses, the child may not feel accepted (Case-Smith, 1989). We need to emphasize the child's strengths and appreciate small gains, thus promoting parental acceptance and a positive attitude toward the child. To develop a positive self-concept, children must have their strengths acknowledged.

As infants become toddlers and then preschool and school-age children, their occupational roles naturally expand. As children develop, they need to function in a range of occupational roles, including student, friend, teammate, and beginning worker. We must analyze what skills and modifications the child will need to function in these roles and then incorporate appropriate activities in our suggestions for the home program. It is important for the child to have an opportunity to function in all age-appropriate roles. The child, whenever possible, must also be given choices regarding the kinds of activities he or she wants to do at home. The opportunity to make choices will help the child develop decision-making skills and will foster a greater sense of internal control.

Summary

Our attitudes and beliefs regarding parent participation and home programs have changed significantly over the past 30 years. We have evolved from believing that, as therapists, we are the experts who teach parents what to do with their child to believing that parents and professionals need to collaborate as equal partners in developing home activities. Today, we are taking the time to listen to families in an effort to serve their needs. As we listen, our attitudes and beliefs regarding parent participation and home programs will continue to evolve. This evolution requires us to maintain a commitment to change and personal growth as we strive to provide family-centered care.

References


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