



## ▶ **Baby Power: A Guide For Families For Using Assistive Technology With Their Infants and Toddlers**

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### **Chapter 2: Parent-Professional Partnerships in Early Intervention**

Rebecca Edmondson discusses the key ingredients in successful collaborative relationships between parents and professionals and the parents' role in screening and assessment and developing individualized plans that include technology.

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Description of chapter:

The author discusses the key ingredients in successful collaborative relationships between parents and professionals, as well as the potential barriers. She discusses the parent's role in the following areas: screening and assessment, developing an Integrated Family Service Plan (IFSP), integrating assistive technology into the IFSP, service coordination, developing a transition plan, and including assistive technology in transition plan.

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## **Introduction**

In keeping with the legal requirements and spirit of the Individuals with Disabilities Education Act (IDEA, 1991), parents are expected and encouraged to play a central role in the early intervention process. While involving parents seems like a logical, natural thing to do, forming parent-professional partnerships has not always proven to be an easy and simple process.

What does the term 'partner' mean? According to Webster's dictionary, 'partner' implies "a joint interest, a companion, a person who shares, or a player on the same team." In addition, when we think of a partnership, we usually think of an agreement between two parties and active participation by both. In early intervention, developing a partnership between professionals and families is essential for good early intervention services. Developing a collaborative partnership, however, may not always be easy. Families and professionals need to be aware of three potential barriers to collaboration.

First, most professionals have been taught to provide services in the traditional, "expert" model. They work within their disciplinary area to evaluate, make recommendations, and provide treatment to individual children. It is difficult for some professionals to move from a discipline-specific to an interdisciplinary model. The interdisciplinary model requires professionals to serve in different roles. This approach demands effective communication with other professionals and families. Most importantly, the interdisciplinary model tries to serve families, not just the child with special needs. Many professionals were not taught to work within this model and are having to make major changes in their attitudes and actions.

Second, parents have traditionally played a somewhat passive role and have primarily been the recipients of the services professionals could provide. With recent legislation and changing national attitudes, parents are expected to play an active role in their child's evaluation and intervention. To this end, parents need to have knowledge of available services and the system. They also need to have effective communication skills, and in general, be a contributing member of an interdisciplinary team. Most parents have not been prepared in any way to fulfill these expectations. It may be difficult, therefore, for some family members to participate as an active member of an interdisciplinary team.

Third, the development of parent-professional partnerships implies a collaborative relationship. Most parents and professionals (hopefully) share the attitude that collaboration will result in better services for young children and their families. A change in behavior, however, has been slow and often difficult. When asked, both parents and professionals agree that there are personal qualities that are necessary for effective partnerships.

Personal qualities necessary for effective partnerships

- mutual respect
- honesty
- trust
- openness
- listening skills
- sensitivity
- communication skills
- empathy

One aspect of early intervention, the use of assistive technology with infants and toddlers, especially requires a collaborative partnership between families and professionals. Families must have their goals and needs met through the use of assistive technology with their children. Decisions on types of equipment, guided by professional knowledge, will impact all aspects of the family's and child's life. Professionals and families must work together to find appropriate equipment and funding sources for assistive technology. All caregivers must be educated in the use and care of the assistive equipment. Choosing and using assistive technology approaches to gain early intervention outcomes most definitely requires the collaborative efforts of families and professionals.

Much has been written about the importance of parent involvement and the need for professionals to work closely with families. Little information is available, however, for parents on "how to" develop their skills and foster effective relationships with professionals. The purpose of this chapter is to discuss components of early intervention. We will also look at parent roles in assistive technology selection and training as a type of early intervention services. General strategies that promote parent-professional partnerships are discussed throughout this chapter.

#### Screening and Assessment

When parents first begin to have questions about their young child's development, it can be a very overwhelming and confusing time. Some parents may feel they have no one to whom they can turn. Others may have already established a relationship with a professional such as their pediatrician or know another family who "knows the system."

In North Carolina, the Division of Mental Health is the lead agency for Part H, the Infant-Toddler Program of IDEA. In other words, the Mental Health system is responsible for screening and providing early intervention services to infants and toddlers at risk for or who have established disabilities.

Screening is the first step toward determining if your child has special needs. Parents, or someone else closely involved with the child, can call the local Mental Health department and ask for the Part H Coordinator. Families and professionals in North Carolina also have access to the Family Support Network (phone # 1-800-TLC-0042), a valuable resource that can provide information, addresses, and phone numbers of most service providers and programs across the state. When contacting the Part H Coordinator, parents should share their concerns about their child's development and ask where to have their child screened. The screening process is free to all families and will help determine if a child needs a more comprehensive evaluation. If so, families may be referred to one of the state's Developmental Evaluation Centers (DECs) at which a child can receive a multidisciplinary evaluation at no charge. Families may call 1-919-733-2815 and ask for the location of their closest DEC.

What is the role of a parent in the assessment process? Parents know their child best and it seems logical that they participate in the evaluation as much as they feel comfortable and to the extent they feel it would be helpful. Some parents may feel that their child will work better if they are not in the room; others may feel that they can help their child do his best during the assessment by

talking to his or by presenting test items themselves.

Some professionals may feel threatened by this loss of testing "expertise" or standardization, or be uncomfortable working with a child with the parent in the same room. Some parents, on the other hand, may not feel comfortable "helping" with the evaluation with professionals watching. They may feel helpless or frustrated when their child will not or cannot do something. Parents should realize, however, that many professionals may feel the same uneasiness and frustration when they cannot get a child to respond.

While it can certainly make a difference who administers a test to a child, it may be even more important that the evaluation process is made clear before, during, and after the actual assessment. Parents have every right to know who will be working with their child and why. If this is not explained prior to the actual day of the initial assessment, parents should feel free to call the evaluation center and ask questions. Each child should be assigned a case coordinator or family advisor at the evaluation center. This would be the person with whom to speak.

For children birth to age three, the evaluation may include some assessment of the family's strengths and needs as they relate to the child's development. Families are not required to provide personal information unless they wish to. They should feel okay asking professionals why that information is important. Again, this can be a difficult time for professionals because the majority of them have not been trained to assess and use information gained about family strengths and needs.

The evaluation may represent the beginning of a long journey for some families. For others, it can either relieve them of fears and anxieties or validate concerns they have had about their child. It is important for both families and professionals to share feelings and concerns. Sharing feelings can help to begin to develop a partnership.

For some families, the professionals at an evaluation center may be the first team they work with. For others families, it may be one of many. Families with premature or very sick infants will probably have experienced a hospital-based team and other teams through Neonatal Follow-Up or Special Infant Care Clinics. Regardless of the level of family experience, an evaluation team will be an important link in getting appropriate early intervention services.

It may be helpful for families to follow these steps during the assessment/evaluation process:

- Introduce yourself and share your concerns prior to the assessment.
- Show an attitude of openness, respect, and trust.
- Find out what will be happening during the assessment.
- Recognize the expertise of both the professional and yourself.
- Ask and suggest ways you might be able to help.
- Ask questions and provide information about your child's development.
- Tell the professionals how typical your child's behavior was during the assessment.
- Discuss the results and ask questions. Make sure you understand what the professionals are suggesting.
- Develop a plan about what the next steps will be with the professionals. Make sure your needs and concerns are addressed in this plan.
- Don't be afraid to ask questions and make your feelings, ideas, and beliefs known.

## **Initial Assistive Technology Assessments**

Some early intervention teams may not have the knowledge or experience to suggest trying some assistive technology options with young children. Parents may have more knowledge in this area. Family members should feel comfortable in asking assessment teams, "Well, what about trying ....?" questions. Children with certain diagnoses or behaviors may be more likely than others to need assistive technology options. These are children with Cerebral Palsy or who seem to be very floppy or overly stiff in their body tone and movements. Other children who are likely to benefit from a range of assistive technologies include those with vision or hearing impairments, feeding problems, and certain syndromes such as Down Syndrome. Use of assistive technology will not keep young children from learning to eat, talk, or walk on their own. Assistive technologies can only help children to grow, learn, and develop.

If families wonder if there may be an assistive technology option that may help their child or may assist them in the care of their child, they should ask any professional working with them. If that person is unsure, families may contact the Resource Center for Assistive Technology and Children Ages Birth-to-Three or the North Carolina Assistive Technology Project office nearest to them. These and other assistive technology resources are listed at the end of this guide.

### Individualized Family Service Plan (IFSP)

One of the most important times for parents to play an active role is during the development of the Individualized Family Service Plan or IFSP. The term "individualized" is key. The IFSP needs to represent the specific needs and goals of the child and also the family's needs in relation to the child. The IFSP is the plan or promise which signifies the hopes and efforts of each team member. Families are equal members of the team. The IFSP should particularly represent the parents' goals. The IFSP process will usually be initiated by the child's service coordinator. The coordinator will be assigned following necessary assessments to make sure a child is eligible for any level of early intervention services.

Before developing the IFSP, parents need to have a clear understanding of the results of the child's evaluation and the available service options. Parents may request that someone who was involved in their child's assessment join them at the IFSP meeting. Someone involved in the assessment should at least make a phone call to the service coordinator to discuss the child's special needs. At the IFSP meeting, parents may need to lead the discussion about their child's needs and share the evaluation results and recommendations. Parents are encouraged to ask questions about service delivery options (home-versus center-based programs or full day versus 2 mornings per week programs).

It will be important to fully understand the options and to determine which services are needed. Early intervention services should meet child and family needs and fit within family routines. For example, if a parent is expected to take his child to physical therapy on Tuesday mornings but works outside of the home, this may not be a satisfactory plan. Parents need to tell professionals what will or will not work for their family. Early intervention personnel need to know a family's schedule and capabilities.

It will be important to listen to the suggestions of the professionals regarding services since this is their area of training and expertise. Only family members know what they can do each day and how much time and effort can be committed to early intervention services. Again, being honest and communicating feelings during the assessment and IFPS meetings is crucial to meeting child and family needs.

After a thorough discussion of a child's strengths and needs and the possible service options, it will

be time for the multidisciplinary team, including family members, to write the IFSP. Parents cannot afford to be passive at this point. It will be important to exercise partnership rights and to participate! The IFSP should include:

- a statement of the child's current levels of development across five domains (physical, cognitive, language and speech, psycho-social, and self-help)
- a statement of related family strengths and needs
- a statement of outcomes expected for child and family
- a statement of needed early intervention services (including use of assistive technology when appropriate)
- projected dates for initiation of services and expected length of services
- name of service coordinator
- the steps to be included for transition to preschool services

When writing the IFSP, teams should be careful to use language that is understood by everyone who is involved. Professionals should attempt not to use technical jargon. Families, in turn, should use words that professionals will understand and try to avoid pet names of the child or certain "baby talk" they may use in their family to represent the child's activities or belongings. For example, if the family says the child will be picked up at day care and taken to physical therapy by "Goo-goo," the professionals may not understand this is "Grandma." In turn, professionals do not need to talk about "an inferior pincer" when they mean a child will finger-feed. While both of the goals listed below intend the same outcome, which one would you prefer?

A. Jessica will demonstrate causal effect relationships by effectively operating the AbleNet Big Red switch utilizing appropriate radial pronation.

B. Jessica will help her mother prepare dinner each night by pushing an adaptive switch to turn on appropriate appliances.

The IFSP is the written plan of the parent-professional team that will be used to generate specific services for a child and his or her family. The IFSP is also one way of evaluating the progress a child has made. The IFSP should be evaluated once a year and reviewed at least every 6 months. As children change and develop rapidly during ages birth to 3 years, more frequent review of the IFSP is recommended.

## **IFSPs and Assistive Technology**

If a child needs a piece of adaptive equipment or any type of assistive technology, this need, possible solution, and outcome should be written into the IFSP. The Individuals with Disabilities Education Act (IDEA) states that public agencies serving children with special needs ages birth through twenty-one must provide the appropriate technologies that are needed by the children. Sample appropriate IFSP outcomes and goals which include assistive technology use are included in each chapter of this guide. The Early Childhood Assistance Center (ECAC) in Davidson, NC (704-892-1321) can help families in writing IFSP goals and in advocating for the equipment they need to help their children to develop, learn, and to become as independent as possible.

### **Service Coordination**

After developing an IFSP, a service coordinator whose job is to link the child and family with needed service providers and systems will be assigned to the family. Parents may want to eventually become their own service coordinators as they are the constant in a child's life and other service providers may come and go. For some children, parents may be the only ones who understand the big picture: strengths, needs, what has been tried and worked or what has been

tried and did not work. Parents may also be the only ones who have complete records of all their child's previous evaluations and therapy goals.

## **Transition Plans**

Currently in N.C., services for children birth to age 3 are provided through Mental Health (Part H) while services for preschoolers (Section 619) are the responsibility of the Department of Public Instruction or the public school system. When a child reaches age three, there will most likely be changes in what kind of services a child can receive and who will provide them. This can be a stressful time as families and professionals struggle to make changes. Parents can help smooth this transition by preparing for it ahead of time. After the child's second birthday, parents should begin talking to service providers about the next year and what needs to be done (evaluations, transition plans) rather than waiting until the month of the child's third birthday.

## **Transition Plans and Assistive Technology**

For children who use assistive technology it is especially important that their new teachers and therapists know how to use the child's equipment. Parents and current service providers should spend an ample amount of time educating the "receiving" placement about the child's needs and how these needs can be met with a particular device or piece of equipment. Transition plans should specifically describe how new service providers will learn to use a child's assistive technology. Appropriate Individual Education Plan (IEP) goals should be written for children ages 3 years and older which include using their appropriate assistive technology.

### **Summary**

Developing parent-professional partnerships in early intervention can be both a challenging and rewarding experience for everyone involved. Like any new skill, learning to work as a member of a team can take time, patience, and a lot of practice. Forming positive parent-professional partnerships will help to make an early intervention system that works for every young child and his or her family.

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