Consumer's Guide

Therapeutic Services for Children with Disabilities

Jessica is a cheerleader on her middle school basketball cheerleading squad. According to her best friend and fellow cheerleader Marcy, she is not just a cheerleader but an "outstanding" cheerleader. She especially enjoys having the cheerleading squad over to her home for slumber parties and going out to the mall with Marcy and David, a special friend, who is on the basketball team.

Aaron, now nine, enjoys hanging out with his friends. Nintendo games are his passion, especially when he is playing "NBA Jam" in head to head competitions. As he likes to say, "I'm just one of the guys."

Carolyn is a four-year old who loves to play at her day care center and in the parks and recreation program, especially gymnastics. Her mother describes her as the life of their family, a joy to her parents and her sisters.

At twelve, **Matt** challenges the best pitchers in his town Little League. He has twice made the all-star team. He has recently made friends with a professional baseball player who is his inspiration; the two correspond regularly.

These could be stories in the lives of any number of children. They happen to be about children with significant disabilities who have benefited from well planned, individually-tailored therapeutic programs.

> **Jessica**, age 12, was born with athetoid cerebral palsy. She cannot walk or talk and needs assistance with all aspects of daily life. That she is a member of the school cheerleading squad is the outcome of the often invisible supports of family, friends and professionals. When Jessica said she wanted to try out for the cheerleading squad, her mother contacted the physical therapist at her school to discuss the possibility. The therapist suggested a prone stander to support Jessica in both standing and moving; she recommended ways to improve access to the football field and basketball court. She also advised bringing together a team of people to help including the school principal, her teacher, and the head of the cheerleading squad—her best friend. In the course of several meetings Jessica's team created the position of "spirit leader" supporting her in a central role on the squad.
>
> From early childhood, **Aaron** has had angry outbursts, frequently leading to destruction of property and attacks on his parents and other children. It was not until Aaron was nearly seven that his mother learned that she and Aaron were experiencing Attention Deficit Hyperactivity Disorder (ADHD). Aaron attended a program, sponsored by his local mental health association, aimed at helping children with ADHD develop skills in socializing and self-control. Parents and special education graduate students organized and carried out the program in consultation with a clinical social worker and a speech-language pathologist. The children shared their feelings and experiences. They participated in community activities, such as movies, playgrounds and sports events. The speech-language pathologist worked with the children in developing socially appropriate communication skills, such as turn taking and initiating conversation. Parents attended a support group where they learned, often from each other, the most effective approaches to supporting their children. Through his two-year involvement in the program, Aaron has realized his dream of being just one of the guys.
>
> **Carolyn** has a diagnosis of spastic quadriplegic cerebral palsy. Since she was six months old, she has been receiving physical therapy and occupational therapy in her home to improve her skills, including the ability to play in various positions and move throughout her house. Now four years old, she is able to pull to a standing position in a reverse walker and use it to walk short distances. Carolyn uses a power

> wheelchair when traveling longer distances and when playing outside. She attends pre-school with her neighborhood friends. The therapists now come to her school. A trained assistant helps Carolyn by modifying the pre-school environment and play materials so that Carolyn can do what her friends are doing.
>
> Shortly after entering pre-school, **Matt** was diagnosed with a progressive hearing loss. Initially a private educator and later a speech-language pathologist worked with Matt and his family to optimize his use of speech and hearing for communication. Once his hearing had deteriorated to the point where his hearing aids were no longer effective, Matt and his family were urged to pursue cochlear implants so that Matt "could continue his life in the mainstream with his friends." They work. The years of speech therapy that Matt received are credited with giving him the ability to understand the crude robot-like sounds that the cochlear implants are able to produce.

Stories like those of Jessica, Carolyn, Aaron and Matt show how well therapeutic services can work. There are stories of disappointment as well where children with disabilities and their families have little to show from their time in therapy.

> **Zachary** was born with hydrocephalus resulting in cerebral palsy, speech impairment and developmental delays. For seven years, beginning at age 2, Zac was taken to a private therapy center to learn to feed himself with the help of various therapists. They tried special eating utensils, plates, and table cloths and favorite foods, all to no avail. Fortunately a change in therapeutic approach led to dramatic improvement. Once Zac's family persuaded the therapist to come to their home and assist Zac during the family's usual dinner time, Zac learned to feed himself using few adaptive devices within a few months. As Zac's mother relates, "the family's schedule and Zac's diet were no longer disrupted by bringing Zac to the center for therapy to learn to eat breakfast cereal in the afternoon."
>
> **Sally**, eighteen months of age, is diagnosed with a generalized developmental delay associated with a rare genetic disorder. Since she was nine months old, she has received one hour of direct physical therapy two times per week through an HMO. Her physical therapist has recommended a decrease in physical therapy hours in view of Sally's slow progress and low level of motivation. Her parents have reluctantly agreed to a gradual decrease in physical therapy in three-month

intervals so long as Sally maintains her current level of motor skills and there is no regression.

Many children with disabilities can use the services of therapists to help them continue to develop, to play, to learn in school, to be active in family and community life, to prepare for adult life and to prevent their conditions from worsening. Trained therapists can assess function, plan interventions, design therapeutic environments, monitor and evaluate progress. However, not all children with disabilities gain from therapeutic services.

This Guide reviews what we know and don't know about employing therapeutic services to improve the lives of children with lifelong disabilities. It does not address therapeutic services designed to meet the post-acute rehabilitation needs of children aimed at restoring their health and function. It is intended to help families and others become more prudent buyers of therapeutic services for children with chronic disabling conditions who are under their care.

There are different types of services that can benefit children with disabilities and that are addressed in this guide. These services may involve the use of assistive technology, other equipment and supplies.

- **Physical Therapy (PT):** Includes services provided by or under the direction of a physical therapist that seek to preserve or enhance a person's motor performance especially in the areas of functional mobility and posture and to prevent further movement problems and physical disability.
- **Occupational Therapy (OT):** Includes services provided by or under the direction of an occupational therapist or certified assistant that help a person to improve fine motor tasks, educational and vocational performance, play, leisure and other important activities of daily life.
- **Speech-Language Pathology (SLP):** Includes services provided by or under the direction of a speech-language pathologist that facilitate communication. Services include prevention, identification and diagnosis,

consultation and treatment of speech, language, and swallowing disorder.

- **Auditory Services:** Includes services provided by or under the direction of an audiologist that facilitate communication and listening. Services include prevention, identification, and rehabilitation of hearing loss and auditory processing disorders.
- **Behavior Therapies:** Includes services provided by a psychologist or other qualified professional that help a person manage emotional and behavioral issues that interfere with school performance, social activities and relationships.

There are other types of therapies (e.g., dance therapy, recreation therapy, music therapy, art therapy and many others) that allow for self expression and, like the basic services, can work to improve motor performance, balance, self-esteem, communication and behavior. These therapies may be used in conjunction with the basic therapeutic services discussed in this guide.

What does the law say about children with disabilities and therapy?

The value of therapeutic services for children with disabilities has long been recognized in law. The Individuals with Disabilities Education Act (IDEA) passed more than twenty-five years ago recognizes the need for therapeutic services to support the development of children with disabilities. Part B mandates special education and related services for children with disabilities ages 3-21. Part H supports discretionary statewide early intervention programs for infants (ages 0-2) with disabilities or at risk. Part H identifies OT, PT and SLP as primary early intervention services. According to Part H, these therapies should be driven by family-desired outcomes relating to infant development and family support. Part B identifies OT, PT and SLP as services related to special education. According to Part B, these services should be designed to improve the student’s academic and non-academic performance and his or her transition to community life.

The courts have affirmed and clarified the role of therapeutic services in the schools as manifest in rulings on due process hearings initiated by child advocates. According to the courts, school-based therapy must help a student achieve specific educational goals. The educational goals and related therapeutic goals should be aimed at appropriate functioning in the least segregated setting possible. Services might be provided directly by the therapist or by educational staff in consultation with a therapist.

Who needs the services of a therapist? How will they benefit?

Children who have significant limitations and function below the expectations for other children their age might benefit from therapeutic services. Each profession uses a variety of ways to assess a child's strengths and needs. There are methods that evaluate how children move, play, behave and communicate in their everyday environments. These assessments are child-specific and environment-specific; they compare the child's functioning to actual expectations throughout the day. In some instances, standardized tests may be used to assess a child's abilities relative to groups of other children his or her age. To be accurate, these tests must be sensitive to cultural issues, administered in the primary language of the child, and administered in an environment that the child finds supportive and comfortable.

The findings of studies on the benefits of therapeutic services for children are generally positive. Still, these studies aren't able to point to specific therapeutic techniques that have proven successful across the board for all childhood disabilities. Attempts to identify optimum service amounts, frequencies and intensities have met with little success. Researchers have had difficulty separating the effects of one therapy from others let alone from the effects of motivation and other factors in the children’s environment. The growing move from traditional, hypotheses-testing research to more discovery-oriented research designs and case-based analytic approaches promises to yield greater insight into what might work best for particular individuals. However, this work is just beginning.

All this is to say is that, at present the effectiveness of therapeutic interventions for children with disabilities must be established on an individual basis. Therapies must be viewed as trial procedures with ongoing monitoring of progress and periodic reassessments. If within an agreed amount of time, the therapeutic services aren’t having an observable and desirable effect, the intervention should be modified or discontinued.

What therapeutic practices work best?

More research is needed before it will be possible to suggest particular techniques for specific types of childhood disabilities. However, there is a growing body of evidence indicating favorable results when therapeutic services are:

- Designed to achieve practical outcomes that will help the child in everyday life
- Planned and provided as part of a collaborative effort of a qualified and experienced team of therapists, educators, and family members
- Provided in a variety of natural settings

Therapeutic Services should aim for results that make a meaningful difference in the life of the child and family

The goals of therapeutic services for children with disabilities should be to enable them 1) to do things for themselves that would otherwise have to be done for them by family, friends or paid caregivers; 2) to play, attend school, participate with friends and family in other community activities, and prepare for life as an adult; and 3) to avoid the premature deterioration of function and health.

Progress should be measured with these goals in mind. Progress measured simply in terms of discrete skills, *e.g.* leg strength and tonicity, increased vocalizations or improved scores on one of the achievement batteries for children, means little unless it makes a real difference in the lives of the children and their families. Therapeutic services driven by practical goals can lead to very different results than goals expressed only in terms of changes in discrete skills.

For example, in the past many children with cerebral palsy have had to attend a special school or special classes. Common therapeutic goals were to increase leg strength and joint mobility with the hope that the child might someday walk. They were never required to move quickly and independently from one place to another. When children with disabilities attend regular classes at school with friends, a practical goal might be that they would use a motorized wheelchair and move independently in and around the school grounds. This changes the emphasis toward a functional outcome and program that should enable the child with a disability to participate in and benefit from school and community life more fully.

Similarly, speech, language and hearing programs driven by practical goals might lead to the use of augmentative communication devices as opposed to vocalization programs for some children. Occupational therapy programs driven by practical goals would be more likely to focus on the use of computers and printers than on improvements in pencil grasp. Vocalization programs, pencil grasp, gait training and other traditional therapeutic approaches would be provided only if the result were likely to be intelligible speech, legible writing and independent mobility.

The chance of success is much improved when therapeutic interventions are collaboratively planned and provided by a qualified and experienced team of therapists, educators, and family members.

The best way to arrive at sensible goals and to identify ways to achieve them is to draw upon the skills and experience of family members, teachers, pediatricians or other important people in the child's life as well as the therapists. The child and family must ultimately decide the outcomes they wish to pursue. It should be an informed decision that considers the preferences of the child and advice from relevant professionals. This advice should be based on assessments of the individual child's capacities and competencies relative to practical goals and on experience with different therapeutic approaches. Professional advice should be combined with information on what motivates and works best with the child from those who know the child well.

Insightful and effective advice can derive as much from experience as from professional training. States impose different educational and practical requirements for therapists to practice. While nearly all states require that therapists be licensed or certified, they do not require specific training in working with children with disabilities and in the application of assistive technology. The amount of continuing education required to maintain licensure varies among states. An increasing number of states are licensing paraprofessionals with more limited training to practice under the supervision of a licensed therapist.

More than one profession may have something to contribute. For example, in order for a child to learn to communicate effectively with her peers, her parents, and her teachers, a speech language pathologist may provide expertise about language development and the use of high tech and low tech communication devices. An occupational therapist may help design the devices and suggest environments that would facilitate good communication. A physical therapist may identify the best body positioning for accessing an augmentative communication device. A behavioral therapist may suggest strategies for dealing with the early frustration that the child is likely to experience in dealing with the new technology.

Family members, teachers and others should work with the therapists to decide what’s best for the child, and should be enlisted and trained to help. Therapists should be looking for ways to make the interventions workable not only for the child but for the family members, teachers and others called upon for support. Therapeutic interventions must be a team effort where the input of each member is valued and where all members are working together.

> Children learn skills more quickly when they are taught and applied in the actual setting and situation in which they will be used.

Therapeutic services should take place where children typically apply the skills that the therapeutic service is designed to improve. When therapeutic activities are provided in the natural environment, children tend to better understand the purpose and engage more easily. When therapy is provided outside of the natural environment, children are expected to transfer the skills learned in the abstract to their real lives. This transfer process may or may not take place, and generally requires more time and money than teaching the skill in the place and at the time needed. Younger children and children with cognitive impairments can have an especially difficult time generalizing skills learned in one setting to another. Still, there are instances when children need to receive therapeutic help in specialized environments, like a therapist's office, where there is special equipment or where special techniques are best applied.

Sound therapeutic approaches are based on the results of assessments which include observation and instruction of children in their natural environments, e.g. a speech-language pathologist would assess how and when a student is experiencing difficulties meeting the language demands of his or her curriculum and classroom. Therapy-related activities should be set up to occur throughout the day in the course of the child's daily routines thereby offering continued opportunities to learn and practice. Therapeutic services provided in natural environments can also reduce the risk of stigma. Children called out for special treatments or isolated in special schools or classes are more likely to perceive themselves as substantially different and less capable than their non-disabled peers.

Consumer Checklist

Therapists are trained in the principles of good practice embodied in this pamphlet. They understand the value of teamwork, of consultation with children and their parents, teachers and other staff. However, large caseloads, competing time demands, limited and restrictive fee schedules, lack of administrative support and other pressures affect the provision of services. Parents and payers should be sensitive to these problems. However as consumers, parents and payers must focus on the child's needs and be prepared to take whatever steps are needed to make sure that the therapeutic services benefit the child.

The answer to these six fundamental questions should be YES:

1. Do the child's therapeutic goals make practical sense; will their achievement make a real difference in the lives of the child and family?
2. How is the child's progress being measured? If thechild is not progressing, is there a formal process to discontinue therapy or change its course (e.g., regimen, therapist, location, type)?

3. Are the therapeutic interventions as much a part of the child's day to day life (at home, school, play, vocational training site) as they might be?
4. Are the parents, teachers and other individuals present in the child's life as involved in the planning and provision of the therapeutic services as they could be?
5. Are the professionals involved in assessing the child and in planning the therapeutic services experienced in serving children with similar disabilities and/or are they consulting with others who are?
6. Are the federal, state, local and private sources of financial support sufficient to underwrite the cost of the planned therapy?

Where to go for further information?

If the answer to any of these questions is unclear or NO, there are a number of organizations listed on the following pages that might provide information concerning good practice. Those organizations marked with an asterisk also have information on sources of funding. Many of these organizations have state and local chapters that can be of help

American Academy for Cerebral Palsy & Developmental Medicine
874-698-1635

American Academy of Child & Adolescent Psychiatry
800-333-7636

American Association of University Affiliated Programs
301-588-8252

American Association on Mental Retardation
800-424-3688

American Occupational Therapy Association (AOTA)
800-668-8225

American Physical Therapy Association (APTA)
800-999-2782

American Psychological Associations (APA),
Division of Early Childhood
202-336-5500

American Speech-Language-Hearing Association (ASHA)
301-897-5700

Association of Maternal & Child Health Programs
202-775-0436

Council for Exceptional Children, Division for Early Childhood
703-620-3660

Federation for Children with Special Needs*
800-331-0688

Federation of Families for Children's Mental Health
703-684-7710

March of Dimes Birth Defects Foundation*
914-428-7100

National Alliance for the Mentally Ill (NAMI)*
800-950-6264

National Association of School Psychologists
301-657-0270

National Association of Social Workers
800-227-3590

National Association of State Directors of Special Education
703-519-3800

National Easter Seal Society
800-221-6827

National Head Injury Foundation
800-444-6443

National Parent Network on Disabilities
703-684-6763

National Spinal Cord Injury Network International
800-548-2673

United Cerebral Palsy Associations (UCPA)*
800-872-5827

*Members of most of these organizations and others have had a hand in the development of this Guide. They participated in an invitational "Think Tank" held March 3-5, 1995 in Alexandria, VA. The formal endorsement of the Guide by these organizations has not been sought nor obtained. The "Think Tank" was organized by the United Cerebral Palsy Associations, Inc.. The Guide was prepared by the Human Services Research Institute. This work was undertaken as part of a grant (91-ASPE244A) funded jointly by the U.S. Department of Education and the U.S. Department of Health and Human Services. Copies of the Guide may be obtained from the Publications Coordinator, Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, MA 02140. Phone 617-876-0426. Fax 617-492-7401. E-mail JWalkrHSRI@AOL.COM.