

The Family Physician's Role with Parents of Young Children With Developmental Disabilities

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Technological advances, coupled with recent federal legislation targeting young children who have developmental disabilities, will increasingly necessitate an expanded role of the family physician in the lives of these children and their families. Of particular importance is Public Law 99-457, the Education of the Handicapped Act Amendments of 1986, which recognizes the importance of the family unit in any intervention methodology that may be provided. This legislation also notes that the active involvement of the family's physician is desirable when designing services appropriate for children with developmental disabilities and their families. Providing support and optimizing positive family interactions are crucial to these children. Recommendations to enable the family physician to address more effectively the unique needs of this patient population include (1) an informal screening protocol, and (2) communication skills that include talking with both parents at the same time, using accurate, nonstigmatizing language when presenting a diagnosis, showing acceptance of and optimism regarding the child, encouraging parents to explain their child's problems to others, helping parents to learn about their children's unique needs, and helping parents to understand how their attitudes affect their child. **J FAM PRACT 1990; 31:288-296.**

During the past decade significant societal forces have commingled with medical advances to increase pressures on the family physician to assume a more active role in the lives of developmentally disabled children and their families.¹ Improvements in medical care, resulting in large part from advancing technology, have decreased the prenatal, perinatal, and postnatal mortality of many at-risk infants.^{2,3} With increasing survival rates of premature, low birthweight, or other at-risk infants, corresponding increases in developmental disabilities may also be anticipated.⁴ Longitudinal studies have consistently presented evidence that many children who survive as a result of medical intervention are at increased risk for mental retardation, blindness, cerebral palsy, learning disabilities, and other developmental problems.⁵⁻⁷ New knowledge and technologic advances in the medical man-

agement of high-risk pregnancies have also resulted in a dramatic rise in the high-risk population of children who subsequently are more likely to have developmental disabilities.⁴

Concern for the needs of families who have developmentally disabled children has resulted in enactment of legislation targeting these populations for professional interventions. Of particular importance are Public Law 94-142, the Education for All Handicapped Children Act of 1975, and its sister legislation, Public Law 99-457, the Education of the Handicapped Act Amendments of 1986. These laws have mandated that school systems expand the scope of their service to include very young children with handicapping conditions. Significantly, parental and family involvement in designing intervention strategies for this population is inherent in these new laws.⁸

A critical component of these laws is the requirement of a *multidisciplinary* evaluation of both children's and families' needs and the development of strategies appropriate to meet those needs. Often a family's initial involvement with community services for disabled children is through its family physician.¹ The importance of the physician in such evaluation and planning activities cannot be underestimated.

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CHANGING ROLE OF THE FAMILY PHYSICIAN

Before passage of Public Laws 94-142 and 99-457, with their transdisciplinary approaches to providing educational and intervention services, physicians were less actively involved in developing and implementing programs for persons with handicapping conditions. Typically, upon referral the family physician performed a routine physical examination to detect medically based handicapping conditions (eg, seizure disorders, sensory deficits, neurological impairments, and genetic disorders such as Down syndrome). Once these disorders were diagnosed, the child was generally referred to psychological, residential, or educational programs, a procedure that minimized further involvement of the family physician. For those children who remained at home, the physician's role was often limited to providing ongoing medical treatment for the child's disorder.

Partially in response to the new federal laws, as well as to evolving concepts of "best practices" in service delivery systems, recent modifications in residency training programs (particularly in pediatrics) have enhanced the physician's role as a member of an interdisciplinary treatment team and as a provider of long-term management.¹ The concept of physicians working with school officials is far from novel.⁹⁻¹² In the family medicine paradigm, involvement in the child's school environment evolves naturally from the total-care philosophy of the specialty.^{13,14} Additionally the family physician's background as a trained diagnostician can be invaluable to the school district, given the mandated responsibility of school systems to identify and track infants and young children with disabilities. The residency-trained family physician has become more cognizant of family social dynamics, including the impact of environmental problems on learning, and can now more capably assess a family's coping skills and those parent-child interactions that have a direct bearing on a child's learning and overall development.

Ideally, the family physician should contribute meaningfully as a team member in local community and school processes involving the welfare of developmentally disabled children and their families, especially when the family has used the physician as their point of entry into the health and social services network. As a continuous provider of care (and in some instances the only such provider), the family physician may have greater continuity with the child and the family than any other professional in the service delivery system. A strong alliance forged between the physician and the family can enable the physician to understand the family's values and coping styles and to establish a rapport that allows meaningful input into family decision making. One of the most impor-

tant functions the family physician may have is that of translator. That is, the physician can serve as an intermediary between (1) the parents and (2) such other medically oriented team members as physical therapists, occupational therapists, speech and language pathologists, and so on. These medically related professionals, who may have never before met the parents, may not be so effective as the family physician in presenting their findings and recommendations to parents. The physician's understanding of the medical and social history of the child and family, as well as knowledge of family dynamics, can facilitate communication of medically related information to the family in a nonthreatening and helpful way.

In assessing the ideal level of personal involvement in the special education programming provided by the local school system, the physician must realistically examine his or her own personal skills and attitudes. Interests and abilities among family physicians vary widely. Individuals so motivated may choose to participate actively in a variety of assessment and intervention activities. In some cases, the family physician may serve on the school evaluation team, particularly when important medical issues for the developmentally disabled child are at stake. In fact, such participation is mandated by law in some states. Typically, the team begins with an initial screening during which indicators of developmental disabilities are evaluated. A knowledge of family dynamics may also help the family physician play the "translator" role within the education planning process as well.

USE OF SCREENING TOOLS

A primary and most significant function of the family physician when working with the family of a disabled child is the early identification of possible developmental delays or disabilities. Initial concerns may have arisen at the onset of pregnancy, as certain conditions signal high risk. These conditions include, but are not limited to, (1) parents from low socioeconomic status who live under impoverished substandard conditions, (2) maternal age under 15 or over 40 years, (3) mothers with a history of difficult pregnancies, (4) mothers with chronic health disorders or physical conditions (such as diabetes) that interfere with pregnancy, (5) parents with family histories of congenital abnormalities, (6) drug usage, and (7) obstetric complications.¹⁵

Commercially available screening tools may be useful to the family physician in initially identifying developmental delays and disabilities in the infant, toddler, or preschooler. Time constraints, however, often make such screening instruments difficult to use routinely with all children. For example, the commonly used Denver De-

Developmental Screening Test (DDST),¹⁴ which contains over 100 items in four general developmental areas, may be too long for routine use. In addition, generalized developmental screening instruments may fail to identify specific medical problems.

As an alternative, these instruments might be informally summarized into a pediatric protocol to be used by family physicians in the clinic. In such a protocol a developmental screening section can be incorporated into the general examination of both the mother and the child at a 2-week follow-up visit. Developmental milestones and related observations identified by the family physician as being indicators of potential developmental delays or disabilities are assessed and recorded on a development form (Figure 1). Though decisions about the optimal time for such screenings will vary among family physicians, one suggestion is that assessments occur at the following ages: 2 weeks, 2 months, 4 months, 6 months, 12 months, 15 months, 18 months, 2 years, 4 years, at any point between 6 and 11 years, 12 years, and 15 years.* Should questions emerge based on this informal protocol, a more comprehensive screening evaluation such as the DDST or the Preschool Attainment Record (PAR)¹⁶ might then be completed. Any observation that deviates from established norms at a particular age would then provide a basis for the family physician to conduct more in-depth assessments or to refer the child to another specialist or other service provider. Postnatal concerns may arise from routine examinations or from comments and concerns of the parents. Specific informal observations sometimes overlooked include responsiveness to loud noises, an absence of reflexive behaviors, development of the basic motor skills identified in Table 1, the failure to acquire expressive language by the age of 2 years, and the baby's response to a novel object (inquisitiveness and reaching).¹⁷

THE FAMILY PHYSICIAN AND SOCIAL SUPPORT

Recent and ongoing rapid advancements in medical, technological, and pharmaceutical interventions for children with disabilities will likely result in even greater responsibility being placed on the family physician in providing necessary services to the children and their families. Especially when working with young disabled children, professionals increasingly are being asked to conceptualize the entire *family* as the recipient of services, not just the disabled child. In fact, when providing services to disabled infants and toddlers, Public Law 99-457 requires

that the intervention be an individualized family services plan (IFSP), not the more familiar school-based and child centered individual education program (IEP) currently required for school-aged children with disabilities. Targeting the family of the young disabled child as the recipient of services has significant implications for the family physician, whose role will be extended beyond medical caregiver.

Given that the home environment is critically important to the long-term outcome of young children who have developmental disabilities,¹⁸⁻²¹ various models have been developed to assist physicians and other professionals working with parents to influence the course of child development.²² A social support network especially contributes to the parents' well-being and to the subsequent development of their children.²³ Although the exact nature of the relationship between social support, stress, and human adaptive functioning is unclear,²⁴ several positive effects that result from social support include (1) fulfilling the need to belong, (2) alleviating the effects of negative stress, (3) restoring hope and morale, and (4) enhancing the ability to use skills in new situations.^{25,26}

POSITIVE INTERACTIONS WITH FAMILIES

That a family's reactions may vary on learning that the child has developmental problems is well documented. Gargiulo²⁷ proposed that parents go through three phases of reactions to the diagnosis of a handicapping condition, each of which may be further subdivided. In the first phase, parents first experience shock at the diagnosis, followed by denial and then grief and depression. In the second phase, parents develop ambivalence about the situation, followed by guilt, which may then lead to anger, followed by shame and embarrassment over the condition. In the final phase, parents engage in bargaining, in which certain offers are made contingent upon their child's improvement. This bargaining stage is ultimately followed by adaptation and reorganization, with acceptance and adjustment developing as the final stage.²⁷ All parents can be expected to experience these various reactions to varying degrees, and the family physician will likely encounter one or more of these reactions from the moment of voicing a suspicion or making a diagnosis of a developmental problem.

Since the impact of the diagnosis can be overwhelming for parents, the family physician should be prepared to present diagnostic evidence in an objective but sympathetic manner. Some important considerations in presenting the initial diagnosis and enhancing support given to the families are as follows:

Tell both parents at the same time. Many families

*A copy of the protocol from which Figure 1 was developed is available from the senior author on request.

2 WEEKS

DATE: _____ **AGE:** _____

<p>Weight _____ % _____ Length _____ % _____ Head Circumference _____ % _____ Temperature _____</p> <hr/> <p>DEVELOPMENTAL SCREEN: Prone lifts head _____ Regards face _____ Responds to noise _____ Other _____</p>	<p style="text-align: center;">INTERVAL HISTORY</p> <p>Prenatal & delivery:</p> <p>Social & economic:</p> <p>Bonding:</p> <p>Exposure to TB:</p> <hr/> <p style="text-align: center;">NUTRITION</p> <table style="width: 100%; border: none;"> <tr> <td style="width: 33%;">Breast _____</td> <td style="width: 33%;">Formula _____</td> <td style="width: 33%;">Vitamins _____</td> </tr> <tr> <td>Duration _____</td> <td>Quantity _____</td> <td>Flouride _____</td> </tr> <tr> <td>Frequency _____</td> <td>Frequency _____</td> <td>Iron _____</td> </tr> </table>	Breast _____	Formula _____	Vitamins _____	Duration _____	Quantity _____	Flouride _____	Frequency _____	Frequency _____	Iron _____
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PHYSICAL EXAMINATION										
<p>Bonding _____ General appearance _____</p> <p>Skin _____ HEENT (RR) _____ Abdomen _____</p> <p>Cardiorespiratory _____ Femoral pulse _____</p> <p>External Genitalia/Anus _____ Back/extremities _____</p> <p>Hip abduction _____ Reflexes _____</p> <p>LAB: Anemia (high risk) _____</p> <p style="text-align: center;">Screen for PKU & T4 (yes/no) done in hospital</p>										
TEACHING TOPICS										
<p>CARE: FMC infant care booklet _____ Skin/scalp _____</p> <p>Foreskin care _____ Sibling jealousy _____</p> <p>Sleep position _____</p> <p>PREVENTION: Crib safety _____ Car seat _____</p> <p>Home hot water (lowered to 100°- 120°F) _____</p> <p>Smoke detector _____ Second-hand smoke _____</p> <p>ILLNESS: How to take temp (rectal) _____</p> <p>When to call doctor _____</p> <p>Polio vaccine (parents) _____</p>										
COMMENTS:										

Figure 1. Postnatal examination with developmental screening. Excerpted from a Pediatric Protocol developed by Jamie D. Howard, MD, Department of Family and Community Medicine, University of Arkansas for Medical Sciences, with permission from the author.

TABLE 1. BASIC MOTOR SKILLS LEARNED BY THE DEVELOPING BABY

Motor Skill	Behavior	Average Age Learned
Head control	The baby can lift and turn his head from side to side. The baby will first lift his head while on his stomach. After this, he can hold his head up independently while he is being held, and later while he is on his back.	Birth-3 mo
Rolling over	The baby will first purposefully roll over from stomach to back, and later from back to stomach. The baby may accidentally roll over before this becomes a learned skill.	5-6 mo
Sitting	The baby can sit at first only with assistance. Later, the baby can assume a sitting position independently. The act of sitting is learned by repetition, and is accomplished by the baby pulling himself up from a lying position or by falling down from a standing position.	6-9 mo
Pre-walking locomotion	The baby uses a number of different motions intentionally to get around before learning to walk. Wriggling on the belly, pulling with the arms, scooting in a sitting position, or "bear walking" on all fours are a few examples. Also at this age the baby will creep or crawl on hands and knees.	7-10 mo
Standing	With help, the baby can stand long before doing so independently. He will quickly build on this skill by holding on to furniture and pulling up. Finally, he can stand without additional support.	8-14 mo
Manipulation	The baby learns to manipulate objects in a series of steps ranging from simple (grasping a medium-sized object at 4 mo) to complex (neatly stacking 6 cubes at 2 yr). After learning to grasp, the baby learns to transfer the object to the other hand. Soon afterwards, small objects (like a pea) can be grasped, but lack of coordination prevents the baby from being able to pile up stackable objects. Over a 9-mo period the baby becomes competent at stacking cubes 6 high.	4-24 mo
Walking	One month after first standing alone, the baby will successfully attempt to walk, and within a few days he is walking (although shakily). Complex walking skills begin at 9-11 mo with assisted walking, and progress to standing on one foot by age 3 yr. The baby begins to walk alone usually by 15 mo, and 3 mo later running will be attempted. Running often takes 6 mo to master and during this time the baby begins to walk up the stairs one foot after the other on the same step. By age 3 yr, the toddler walks up the stairs using alternating feet, and 1 yr later will be walking down the stairs alone.	9-48 mo

report dissatisfaction with the manner in which they were first informed of the child's problem as well as the lack of support thereafter.²⁸ If the developmental disability is recognized during the neonatal period, the baby should be brought to the mother, with the father present, as soon as possible following delivery. The images of an abnormal child that can arise when an infant's presence is forestalled are usually worse than reality.²⁹ Bringing the baby to both parents is especially important in those maternity wards where the mother might be given information before the father. By relegating the father to a position in which he receives information after the mother and therefore perceives his role as being less important than the mother's, the stage is set for the development of abnormal family interaction patterns in the future.³⁰ It is important that the family physician avoid doing anything that can create a rift in the psychological relationship between the

parents or any other family members. For single-parent families, other family members (such as a grandparent, aunt, or uncle) could be invited to be present when information is given regarding a suspected or diagnosed disability. Significant emotional support for the parent(s) can be gained when the information is presented to the entire family.

Use accurate, nonstigmatizing language when presenting the diagnosis. Outdated terms, such as mongoloid or cripple, should be avoided, as such words have a pronounced inhibitory effect on the adaptation process, including the early bonding and attachment necessary for positive development. Since the family physician is dealing with human beings who are more alike than they are different, it is more appropriate to emphasize the child's normal features (as opposed to focusing on the child's

abnormality) when presenting the nature of the child's condition.

Show acceptance of the child and optimism regarding the child's future. The physician can provide a real service to families of children with developmental disabilities by demonstrating initial acceptance of the child and by maintaining an optimistic perspective of the child's future. Such actions can model parental acceptance of the child. The importance of the family physician's demeanor when relaying diagnostic information cannot be overemphasized. In recalling how he was informed of his son's Down syndrome, one father noted that when a child is born apparently healthy, "the doctors do not recount for parents all of the problems that could happen to their child, like drug involvement, flunking out of college, sexual promiscuity, or teenage suicide. However, when a child with Down syndrome is born, the doctors only point out the negative."³¹ Encouraging communication among family members is important at this time as well, given that the parents may repress their emotional reaction if an appropriate outlet for communicating such emotions is not facilitated by the physician.

Encourage the parents to explain the situation to friends and relatives. In so doing, a dual purpose will be achieved. First, by explaining the condition to others, parents learn to accept their child's problems. Second, the parents can encourage more accepting attitudes in others, which will have a positive impact on the child's support system across his or her entire social environment.

Help the parents to learn about their child's special needs. The family physician should be prepared to make referrals, both to specialists and to other parents of children with developmental disabilities. For example, most local chapters of the Association for Retarded Citizens provide such parental contacts and support when a child with a medically identifiable condition involving mental retardation (eg, Down syndrome) is born. These organizations are an invaluable source of support. As consumers of health care services, parents have a right to additional information regarding their children. Thus, various opinions about the child's health status should not be viewed negatively by the physician, but be welcomed.

To facilitate the development of a support base, the family physician must be knowledgeable about community and organizational resources. Table 2 lists national agencies that provide information and support to families with disabled children. Many of these organizations also have state or local chapters, which may additionally offer both emotional support and practical approaches to the situation.

In helping parents begin to understand the service delivery options for their handicapped child, the family physician should consider the desirability of less restrictive home- or community-based early intervention programs

before recommending to parents more restrictive alternatives such as institutionalization. During the 1960s, significant numbers of general practitioners believed that immediate institutionalization after a diagnosis of mental retardation was appropriate for most children.^{30,32} Since that time, however, professional consensus has shifted dramatically, with most professionals recognizing that these mentally handicapped children usually do best in the most normal situation possible; that is, the home with support services offered as needed.^{33,34}

It is crucial that the family physician be aware of all existing resources in the region in which he or she practices to fulfill the parents' very real need for support on being told that their child has a developmental disability.^{9,11,13} Families who at first resist referrals to other agencies may come to view such interventions in a more positive light as the child's disability becomes more pronounced or as the family becomes more accepting of the child. The physician may wish to have on hand educational brochures dealing with the most frequently occurring developmental disabilities. Many national organizations are willing providers of attractive, professionally developed visual materials that can impart considerable information to parents about their child's condition.³⁵ Simply requesting copies of these materials and making them available in the office can be a tremendous asset to the physician when parents and families need information quickly.³⁶

Help the parents learn how their own attitudes will affect their child. The manner in which parents view their child affects the nature of their interactions with the child over time, which in turn greatly influences the prognosis for the child. Thus, it is important for the family physician (or associated professional with counseling skills) to explore the parents' attitudes, and to explain how negative attitudes can adversely affect the child's developmental outcome. The physician should be familiar with the classic studies addressing self-fulfilling prophecies, ie, when significant persons in a child's environment expect less of the child, less attention and fewer opportunities for growth and development result in diminished developmental outcomes.³⁷ Such studies have direct implications for family physicians working with parents of developmentally disabled children.

CONCLUSIONS

The evolving multidisciplinary treatment of children with developmental disabilities places added pressures and demands on the family physician. In those frequent cases where an intellectual, sensory, emotional, or physical handicap is recognized because of medical characteris-

TABLE 2. SUPPORT ORGANIZATIONS FOR FAMILIES OF CHILDREN WITH DISABILITIES

General Organizations

Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091. Includes over 50,000 teachers, teacher educators, administrators, researchers, and other professionals involved in the education of exceptional children and adults.

Mental Retardation

American Association on Mental Deficiency, 5201 Connecticut Avenue NW, Washington, DC 20015. Primarily includes researchers, teacher educators, and psychologists interested in mental retardation.

Association for Retarded Citizens, 2709 Avenue E East, Arlington, TX 76011. An advocacy organization including parents and professionals, with active chapters in most states.

Division on Mental Retardation, Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091. Includes teachers, teacher educators, researchers, and other members of CEC working with mentally retarded persons from preschool on.

Learning Disabilities

Association for Children and Adults with Learning Disabilities, 5255 Grace Street, Pittsburgh, PA 15236. An active organization of parents and educators that serves as an advocate for children with learning disabilities.

Council for Learning Disabilities, Department of Special Education, University of Louisville, Louisville, KY 40292. An organization for professionals who work with persons having learning disabilities. Publishes *Learning Disabilities Quarterly*, holds an annual conference to disseminate research and information, and promotes standards for professionals.

Division for Learning Disabilities, Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091. Includes teachers, teacher educators, researchers, and other members of CEC who work with or on behalf of persons with learning disabilities.

Emotional Disturbance

American Association for the Advancement of Behavior Therapy, 420 Lexington Avenue, New York, NY 10017. Includes psychologists, educational researchers, and educators (primarily at the university level).

Council for Children with Behavior Disorders, Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091. Includes teachers and teacher educators interested in behavior disorders. Produces an annual publication titled *Teaching: Behaviorally Disordered Youth*.

National Society for Children and Adults with Autism, 621 Central Avenue, Albany, NY 12206. A support and advocacy organization for individuals with autism.

Communication Disorders

American Speech-Language-Hearing Association, 10801 Rockville Pike, Rockville, MD 20852. The major professional organization concerned with speech and language. Serves as a certifying agency for professionals who provide speech, language, and hearing services. Publishes several journals, sponsors research in communication disorders, and provides a comprehensive Guide to Professional Services, which also includes information on accredited training programs. Also sponsors the National Student Speech, Language, Hearing Association, which has chapters on many college and university campuses.

Division for Children with Communication Disorders, Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091. Includes teachers and communication disorders specialists who work with exceptional children. Sponsors sessions at state, provincial, and national conferences. Publishes the *Journal of Childhood Communication Disorders* twice yearly.

Hearing Impairment

Alexander Graham Bell Association for the Deaf, 3417 Volta Place NW, Washington, DC 20007. Provides brochures, books, software, audiovisual materials, and other information on hearing impairment, with an auditory-oral emphasis. Publishes the *Volta Review* for professionals, *Our Kids Magazine* for parents, and *Newsounds* newsletter. Sponsors organizations for teachers, parents, researchers, and oral deaf adults.

Gallaudet University, 800 Florida Avenue NE, Washington, DC 20002. Has in its bookstore one of the most complete collections of professional and popular literature about hearing impairment, communication, education, psychology, and related topics. Also has children's sign language books that appeal to many readers. Provides free catalogs of book lists; arranges tours of the Gallaudet campus for Washington visitors.

National Association of the Deaf, 814 Thayer Avenue, Silver Spring, MD 20910. A clearinghouse for information about education, employment, legal issues, communication, technical aids, and other topics. Sponsors activities for deaf adults, children and parents.

National Cued Speech Association, P.O. Box 31345, Raleigh, NC 27622. Provides information, training, and publications on the cued speech system of identifying sounds and supplementing speech reading skills.

Visual Impairment

American Foundation for the Blind, 15 West 16th Street, New York, NY 10011. Provides many publication and films about blindness. Distributes aids and appliances for people with impaired vision. Publishes *Journal of Visual Impairment and Blindness* and *Directory of Agencies Serving the Visually Handicapped in the United States*.

American Printing House for the Blind, 1839 Frankfort Avenue, Louisville, KY 40206. Provides books, magazines, and many other publications in braille, large print, and recorded form. Distributes educational materials and aids specially designed for the blind and helpful publications for teachers. Attempts to register all legally blind US children through state departments of education and residential schools. Also provides recordings and computer materials.

Association for Education and Rehabilitation of the Blind and Visually Impaired, 206 North Washington Street, Alexandria, VA 22314. Emphasizes educational, orientation, mobility, and rehabilitation services. Holds regional and national conferences in the United States and Canada. Publishes *Education of the Visually Handicapped* and a *Yearbook* compiling recent literature in this field.

Division for the Visually Handicapped, Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091. Presents sessions of interest to educators at international, state, and provincial conferences of the Council for Exceptional Children. Publishes a quarterly journal on educational topics.

National Association for Parents of the Visually Impaired, 2011 Hardy Circle, Austin, TX 78756. Provides practical information for parents. Sponsors parent groups in several areas. Holds conferences and workshops for parents and teachers.

National Federation for the Blind, 1800 Johnson Street, Baltimore, MD 21230. The largest organization of blind people in the United States, with many state and local chapters. Provides publications and films that emphasize the rights and capabilities of people with blindness. Seeks to involve persons with blindness in education and employment and to avoid discrimination. Also sponsors activities and publications for parents of children who are blind.

TABLE 2. CONTINUED

Physical Handicaps

- Cystic Fibrosis Foundation, 6000 Executive Boulevard, Rockville, MD 20852.
- Epilepsy Foundation of America, 4531 Garden City Drive, Landover, MD 20785.
- Juvenile Diabetes Association, 23 East 26th Street, New York, NY 10010.
- Muscular Dystrophy Association, 810 Seventh Avenue, New York, NY 10019.
- National Easter Seal Society, 2023 West Ogden Avenue, Chicago, IL 60612.
- Spina Bifida Association of America, 343 South Dearborn Street, Chicago, IL 60604.
- United Cerebral Palsy Association, Inc. 66 East 34th Street, New York, NY 10016.

Severe Handicaps

- ABLENET, 360 Hoover Street NE, Minneapolis, MN 55413. Offers information and publications on the use of automated learning devices, microswitches, and other technology with persons who have severe handicaps. Has available for purchase a book by Jackie Levin and Lynn Scherfenberg, *Breaking Barriers: How Children and Adults with Severe Handicaps Can Access the World Through Simple Technology*.
- The Association for Persons with Severe Handicaps, 7010 Roosevelt Way NE, Seattle, WA 98115. Its journal and monthly newsletter disseminate a wide variety of useful information to teachers, parents, administrators, researchers, and others. Its annual convention provides the major forum for the exchange of new developments relating to the education of persons with severe handicaps. Its many state and local chapters also sponsor conferences and activities.
- Center on Human Policy, 724 Comstock Avenue, Syracuse, NY 13244. Provides reports and other resources on the integration of people with severe handicaps into community life. Also distributes materials encouraging the development of positive attitudes about persons with disabilities in schools and the media.

Department of Specialized Educational Services, Madison Metropolitan School District, 545 West Dayton Street, Madison, WI 53703. In cooperation with the Department of Studies in Behavioral Disabilities at the University of Wisconsin, has been especially active in developing programs of instruction for children with severe handicaps and in seeking to facilitate integration with nondisabled students. Has available for purchase a number of curriculum guides and other materials.

Helen Keller National Center for Deaf-Blind Youths and Adults, 111 Middle Neck Road, Sands Point, NY 11050. Offers training programs for persons with impaired vision and hearing and consultation to agencies providing services to this population. Publishes *Directory of Agencies and Organizations Serving Deaf-Blind Individuals*, curriculum manuals, and other informational materials about deaf-blindness.

Parent Support

- Closer Look, 1201 16th Street NW, Washington, DC 20036.
- National Center on Child Abuse and Neglect, US Department of Health and Human Services, PO Box 1182, Washington, DC 20013. Offers National Child Abuse Hotline with a toll-free number: 800-422-4453.
- National Network of Parent Centers, 9451 Broadway Drive, Bay Harbor, FL 33154.
- National Parent CHAIN, 515 West Giles Lane, Peoria, IL 61614. A volunteer organization to establish a national information and education network for persons with handicaps and their families.
- Pacer (Parent Advocacy Coalition for Educational Rights) Center, 4701 Chicago Avenue South, Minneapolis, MN 55407.
- Parents Educational Advocacy Center, 116 West Jones Street, Raleigh, NC 27611.
- PEP (Parents Educating Parents) Project, Georgia Association for Retarded Citizens, 1851 Ram Runway, Suite 104, College Park, GA 30337.

tics, the family physician is immediately turned to for support by families of such children. Because of the natural psychological trauma associated with the initial identification of a child with special needs, families are particularly vulnerable and in need of social support from an empathetic, well-informed family physician. Skillfully delivered support from the family physician who responds to the entire family and not just the child with the disability can be a most significant contribution to the ultimate functioning of that child and family.

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