

## Community Resources for Children With Special Healthcare Needs

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Families' lives are inexorably altered as a consequence of having children. When a child is found to have a disability, a crisis situation is perceived by most families.<sup>1</sup> Initially, stamina, optimism, and the sense of control are sapped. The impact varies depending on the family's beliefs, coping style, and resilience, and the availability of local community resources. Challenges in childrearing vary from minor day-to-day aggravations (which have a cumulative effect) to major catastrophes that are superimposed on the family's background level of stress.<sup>2</sup>

The family unit itself is extremely important in its ability to raise a child with special healthcare needs (CSHCN). Some families are relatively self-supporting and cope well; others will require substantial external resources. In either case, families will have fluctuating needs, with even the most resilient

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### EDUCATIONAL OBJECTIVES

1. Increase physician awareness of the need for community support for families with children who have special healthcare needs.
2. Assist physicians caring for children with special healthcare needs in identifying and locating local and national support resources.
3. Provide information on how to access local and national support resources for children with special healthcare needs and their families.

family needing support at the time of a new crisis. Although parents of CSHCN *do* experience more stress, research suggests that they are as functional and as maritally adjusted as control parents.<sup>3,4</sup>

Physicians and other healthcare professionals can greatly assist parents of CSHCN both by providing medical care and by addressing the related needs of the *entire* family. Physicians can best accomplish this by adopting a "medical home" philosophy that empha-

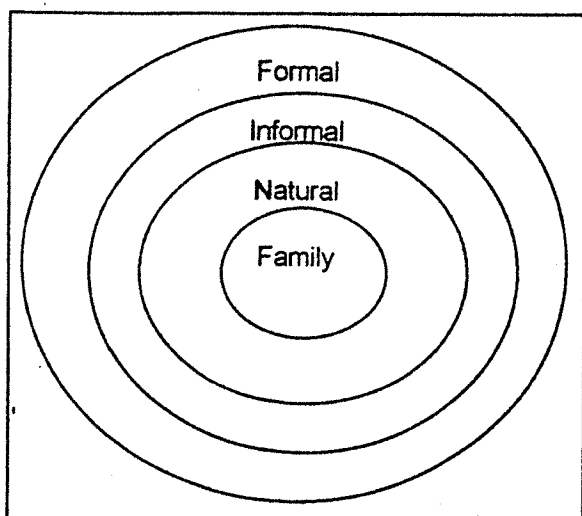


Figure. Levels of support.

sizes community-based, family-centered medical care and quality community resources to support families.

This article has three objectives: (1) to increase physician awareness of families' need for community supports, (2) to identify existing local and national resources, and (3) to provide information to access these resources.

#### WHY DO FAMILIES NEED COMMUNITY RESOURCES?

Families require differing degrees of community supports depending on structural, functional, and external characteristics of the family.<sup>1</sup> *Structural* characteristics that impact a family's need for community supports include whether it is a single-parent household and the age of the parent or parents and their living arrangements (eg, a teen mother living with her own biological family or a blended family). *Functional* characteristics include parental coping styles, sibling issues, and paternal involvement in the day-to-day responsibilities of caregiving. Finally, *external* characteristics (ie, poverty, work schedules, unemployment, distance from extended family members) also impact on the family's need for support when raising CSHCN.

The degree to which community supports positively affect families reflects the degree to which they are accessible and matched to the family's needs. Too often, community resources are dictated by bureaucrats who design services that do not address the actual needs of families or that are not user-friendly. The primary reasons that many families do not access available supports are because they are not aware of them and because of barriers that prevent access.<sup>6</sup>

Resources available to families consist of three levels of support, as shown in the Figure.<sup>2</sup> The inner ring represents the family's *natural supports* and includes

spouses, extended family members, neighbors, and friends. The middle ring represents *informal supports*, which includes social networking with other families of children with disabilities through contacts made in clinics, hospitals, early intervention programs, schools, and, most recently, through the Internet. Cooperative relationships with physicians, nurse clinic coordinators, therapists, teachers, and social workers can also enhance family coping, resilience, and advocacy. Parent support groups, recreational activities, and family conferences are also valuable sources of information, comfort, and support. Finally, in the outer ring are those *formal supports* (financial, legal, and health insurance benefits, respite waiver vouchers, early intervention and special education programs, accessible transportation, and other local, state, and federally supported systems) to which the families of CSHCN are entitled.

Support should begin with the closest and most natural resources. Extended family members can be tremendously helpful to parents and siblings both in relieving the demands of physical caregiving and in psychological and emotional support. This natural support will be adequate for some families most of the time. However, at the time of a new crisis, they may need to temporarily access informal and even formal support systems. Other families will have limited natural and informal supports, and must remain dependent on formal supports. These families are at highest risk for social isolation and demoralization.<sup>2</sup>

In order to maximally benefit from all levels of community support, families of CSHCN need to develop (1) communication skills to express their needs and to evaluate discrepant inputs from various professionals, (2) case management skills to coordinate care from multiples sources, and (3) advocacy skills to gain information and access to services existing within their community and nationally. Families cope best when they have developed these skills and thereby become "empowered." While trying to accomplish all of this, they need to maintain their health, their stamina, and their optimism.

#### WHAT IS THE PEDIATRICIAN'S ROLE?

Complaints by families about physician performance regarding CSHCN rarely relate to actual medical care but rather to issues of communication and resource counseling. In a survey of parents whose children were enrolled in early intervention programs, only half of the parents identified their pediatrician as helpful in terms of providing information about support services.<sup>7</sup>

Liptak and Revell<sup>8</sup> formulated a "wish list" of support services through a survey of 519 families with CSHCN (Table). The families were asked to rank-order desired services according to the relative importance of each in maintaining family functioning. The authors also surveyed pediatricians by asking them to

rank-order the same services according to how they perceived their importance to families. There was a considerable mismatch between what supports physicians thought were most important to families and what supports families themselves thought were most important. Of special interest is the fact that parents rated "information about community resources" as the most important item. In the same survey, physicians recognized their need for ongoing training regarding available community resources in order to fulfill their role as care coordinators.

In general, most parents feel that it is the physician's responsibility to help fit medical care priorities into the overall management picture. Although they do not view their pediatrician as a social worker, they do look for guidance and support, mainly in the form of collaborative (sometimes creative) problem solving and resource management.

#### HOW DOES ONE BECOME INFORMED?

Community and national resources, especially the category of formal supports, are constantly changing. It is important that the clinician become informed and keep up to date. A superb resource for physicians and families alike is *Exceptional Parent (EP)* magazine. (To subscribe to *EP* magazine [\$32/yr], call 800-562-1973, write to *EP*, 555 Kinderkamack Rd. Oradell, NJ 07649-1517, or e-mail to <http://www.familyeducation.com>.) It is written by parents and professionals, and serves as a forum for sharing information relevant to CSHCN. *EP* is practical in nature, high in quality, and inexpensive. Annual focus issues pinpoint relevant topics such as financial planning, camps, health issues, adaptive equipment, advocacy and support organizations, financial resources (including how to write a "Special Needs Will"), and so on. We recommend that every pediatrician's office maintain a subscription to *EP* for the waiting room. *EP* also features a monthly "Search and Respond" section that provides families with an opportunity to seek out other families with children with similar disabilities and needs. (Parents can search or respond by writing to the same address.)

Each year, *EP* updates and publishes its *Resource Guide* listing national parent support, parent-to-parent, and advocacy groups, state assistive technology centers, manufacturers of specialized equipment, competitive sporting opportunities, and accessible national parks, camps, and other recreational options. One of the most helpful lists in the *Resource Guide* is the one entitled "National Resources for Specific Disabilities and Conditions." Large and nationally known agencies (eg, Spina Bifida Association of America and United Cerebral Palsy) as well as new and smaller organizations are listed. Some are quite specific (eg, the 5p Society, a support group for families of children with Cri du chat syndrome); others are more general (eg, a national support group for fathers

T A B L E

#### A "Wish List" of Support Services Taken From a Survey of 519 Families of CSHCN

Service	Family Rating	Physician Rating
Information regarding community resources	1	14
Financial information/help	2	5
Parent support groups	3	3
Recreational opportunities	4	13
Psychological services	5	9
Vocational counseling	6	8
Summer camp	7	19
Dental treatment	8	16
Respite care	9	1
Help with behavior problems	10	4

Adapted from Liptak GS, Revell GM. Community physician's role in case management of children with chronic illness. *Pediatrics*. 1989;84:465-471. Reprinted with permission from the American Academy of Pediatrics.

of children with any disability). The agencies are listed with mailing address, e-mail address, phone and fax numbers (many have 800 numbers), and codes representing the services provided. The menu of services includes, but is not limited to:

1. Dissemination of information via brochures, journal articles, books, and newsletters
2. Networking and matching of families
3. Referrals to local chapters and/or community resources
4. National conferences
5. Participation in national advocacy efforts
6. Fundraising for research endeavors
7. Maintenance of a research registry

The *Resource Guide* is free with the January issue of *EP* magazine or can be ordered separately (by calling 800-535-1910), or it can be purchased at Barnes and Noble "superstores" for approximately \$10.

Many organizations publish and distribute resource lists that are relevant to families of children with the specific condition represented by the organization. For example, the United Cerebral Palsy Association publishes the *Family Support Bulletin*, which provides information regarding resources for children with cerebral palsy.

The Internet is another source of information-sharing that is being increasingly used by families. Many agencies have a web page with information regarding their mission, goals, services, and policies. Almost every commercial on-line information service has electronic disability forums. One need only contact their on-line service for information. *EP*'s disability network can be found on eWorld. It provides (1) an interactive area for CSHCN and their families, (2) a fully searchable database containing resource information, and (3) a bulletin board. Many parent

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support organizations have bulletin boards and "chat rooms" whereby families can maintain contact with other families of children with similar disabilities around the world. The Internet has also become a source of non-peer-reviewed information regarding alternative "treatments" for CSHCN. Physician awareness of Internet "testimonials" is helpful when assisting families in evaluating unproven interventions.

Pediatricians seeking information about informal supports in their own vicinity can start by contacting the local early intervention program (EIP). The EIP staff often introduce and facilitate supporting relationships among families of children with similar conditions and needs. The staff can also assist parents in gaining information and accessing other informal supports such as parent support groups, child care options, respite and recreational programs, and so on. Another option is to call the local United Way. Besides fundraising and fiscal oversight of its associate agencies, most United Way agencies publish a directory of private non-profit agencies offering services to families of children with disabilities. Many also operate a telephone "helpline" whereby families and professionals can gain immediate access to information regarding local agencies.

**WHAT COMMUNITY RESOURCES ARE AVAILABLE AND HOW ARE THEY ACCESSED?**

**Informal Supports**

Informal supports vary widely from community to community. Typically, urban areas have a wider variety of programs and the likelihood of "connecting" with a family of a child with a similar disability is greater. Disability-specific multidisciplinary clinics associated with urban medical centers can be helpful in linking families with similar needs.

*Family Support Groups:* Numerous groups developed by parents for parents have evolved over the years. Some represent grassroots local groups that operate out of a family's house; others are subsidiaries or local chapters of national agencies with extensive networking capacity. Both types typically provide regular meetings, moral support, opportunities for networking, family swap programs for child care and seasonal recreational events, and so on. Friends Health Connection is a national non-profit organization that

provides a network to link individuals with disabilities.<sup>9</sup> Call "Find a Friend" at 800-483-7436 or visit the website (<http://www.48friend.com>). WOW (Winners On Wheels) is another national non-profit organization designed to help children (7 to 12 years of age) who use wheelchairs to develop positive self-esteem through peer linkages. Call 800-WOW-TALK or e-mail ([wowtalk@earthlink.net](mailto:wowtalk@earthlink.net)). Sibling support groups and "sib-shops" (workshops for siblings of CSHCN) are becoming quite popular among families. For more information on sibling supports, call the National Information Center for Children and Youth with Disabilities (800-695-0285).

*Advocacy and Empowerment:* Parent Training and Information Centers (PTIC) are operated by disability advocacy groups and strive to "empower" parents to become active partners—collaborators, decision-makers, problem-solvers—with professionals and agency personnel. PTICs are based on the premise that families are best served by helping them enhance their own skills. A listing of local PTICs can be found in the *EP Resource Guide* or by calling the national PTIC office (703-684-6763):

*Day Care:* Because more and more mothers have joined the workforce, child care has become a major issue for all parents. The presence of a child who is disabled or technology-dependent usually means one parent must cease working. If home health care is available, it is usually too limited to permit full-time employment. Finding qualified babysitters is difficult and daycare centers are often not equipped to care for CSHCN. The Americans with Disabilities Act (ADA) of 1990 mandates a reasonable effort to allow access to normal community services such as daycare. In Texas, a program entitled "Child Care Choices" has been developed to help families access daycare within their immediate communities. This agency educates the local child care center employees and provides a temporary extra staff person to give the technical assistance needed to facilitate the child's attendance in the center.

*Respite* (defined as time away from caretaking responsibilities involved in the care of CSHCN) is often quoted as one of the most important supports, especially for parents of children with autism or children who are medically fragile and technology-dependent.<sup>10</sup> Many families have no nearby relatives or the relatives may be reluctant to care for the child with complicated behavioral or healthcare needs. There are several different respite models; one or all may be available in different communities:

1. Center-based respite: Children are cared for in hospitals, nursing homes, residential schools, camps, and hotels for a contracted period of time ranging from a few hours to 1 month. Most agencies offer a sliding fee scale.
2. In-home respite: A trained respite caretaker is paid to come into the person's home and provide

assistance with daily living activities. The parents may remain at home or leave for an outing. The cost usually ranges from \$5 to \$9 per hour unless skilled nursing care is necessary. Through the novel "respite" program, parents receive weekend hotel lodging while a provider cares for the child in his or her own home.

3. Family co-op respite: Families of children with developmental disabilities network with each other to provide reciprocal respite.
4. Emergency respite: Families can access respite services on short notice by making a telephone call any time of the day or night.

Local EIP and special education programs should be able to provide the family with local options. National information centers include the ARCH National Resources Center for Respite (800-473-1727), the National Respite Locator Service (800-7RELIEF), and the Texas Respite Resource Network (210-704-2794 or e-mail [enewhouse@srhc.org](mailto:enewhouse@srhc.org) or visit their website at <http://www.chttop.com>).

*Recreational resources:* Leisure activities are important to the well-being of all persons, whether disabled or not. In the private sector, YMCAs, YWCAs, and Jewish Community Centers across the country have been leaders in the area of recreational inclusion of CSHCN. In regard to vacationing, some travel agencies specialize in making travel arrangements for persons with disabilities. The Travelin' Talk Network (615-552-6670) maintains a helpline to assist persons with disabilities plan "worry-free" vacations. The program is now international and "hosts" can be found in almost every major city. An extensive directory of accessible private and public accommodations, which is updated with quarterly newsletters, is available. CSHCN may receive special discounts and privileges (ie, shorter waiting lines for rides) at some theme parks. Additionally, Disney and Six Flags publish accessibility guidebooks. The National Park Service publishes a book (*Easy Access to National Parks*) prepared by consumers that details accessibility in approximately 50 major national parks. A more general guidebook (*The Complete Guide to America's National Parks*) provides less detailed accessibility information for over 350 parks. (To order, call 800-285-2448.)

Summer camping experiences can be enormously valuable to all children. Besides having fun and learning new skills, organized camping can promote emotional maturity and independence. Group living fosters communication and provides unique opportunities to openly express feelings and to develop relationships. Campers are encouraged to work together and accept one another. The American Camping Association (ACA) accredits camps nationwide and also publishes a directory of accredited camps that serve special populations (800-428-CAMP). Additionally, the ACA has regional offices with

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knowledgeable staff that can assist a family in learning about and accessing a suitable camp. Condition-specific 1-week camps funded by local health agencies (eg, Muscular Dystrophy, Kidney Foundation, Cystic Fibrosis Association, and American Lung Association) may not be listed in ACA materials. One should call the local agency for information regarding dates, eligibility, and costs.

Special Olympics offers a broad spectrum of opportunities and can be accessed through the public school systems. Additionally, Wheelchair Sports USA (719-574-1150) and US Cerebral Palsy Athletic Association (810-577-5070) offer competitive sports opportunities to persons with physical disabilities. Rehabilitation facilities in one's own community can usually provide children with local access to organized sports (ie, wheelchair basketball, tennis, and track competitions) as well as hippotherapy and hydrotherapy programs. Although the scientific literature is sparse on the measurable benefits of these programs, emotional benefits in terms of recreational enjoyment and self-esteem enhancement are apparent.

*Assistive technology:* There are local, state, and national agencies to assist a family in its search for both low- and high-tech devices. The regional "Educational Service Centers" associated with the public school system are a good starting point. There are some very helpful non-profit and commercial agencies that can assist a family find and evaluate assistive devices ranging from van adaptations to computer hard- and software, feeding devices, toys, toothbrushes, and so on. Examples of good resources include Abledata (800-227-0216 or website <http://www.abledata.com>), the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA; 703-524-6686), and the Alliance for Technology Access (415-455-4575). The Alliance began as a joint project of a grassroots parents organization and a major corporation (Apple Computer). There are now centers in almost every state.

*Toys:* The USA Toy Library Association (USA-TLA) is a national network of nearly 400 toy-lending libraries. Parents can "try out" specially adapted toys for a month at a time. To locate the nearest one, the family can call the national office (708-328-0001).

*Clothing:* Information regarding special clothing can be found in the book *The Best 25 Catalog Resources for Making Life Easier* by Shelley Peterman Schwarz.<sup>11</sup> This book contains over 100 resources

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helpful for obtaining a wide range of adaptive clothing ranging from specially designed clothing for children with Down syndrome to clothing with special fasteners for children with poor fine motor skills. To order, e-mail [help@makinglifeeasier.com](mailto:help@makinglifeeasier.com), the website [www.makinglifeeasier.com](http://www.makinglifeeasier.com), or call 601-274-4380.

*Transition:* "Transition" is defined as the passage from child-centered activities to adult-oriented activities. Transition occurs in three main aspects of life: (1) from pediatric health care to adult-oriented health care, (2) from school to work, and (3) from home to community. Successful transition for a teenager or young adult with disabilities usually requires more preparation than for a non-disabled individual. Transition in health care has become a priority issue at the public health policy level, and several transition models are being implemented across the nation. The PACER Center, one of the PITCs serving the upper midwest, has developed a superb transition training program in collaboration with Shriner's Hospital and local physicians in Minneapolis, Minnesota. To obtain a catalog of transition resources, call 612-827-2966 or write PACER at 4826 Chicago Ave S, Minneapolis, MN 55417. Informing the family about available educational and vocational training opportunities as well as independent living options is an important first step.

### **Formal Supports**

Formal supports are those that are federally mandated and publicly supported. Most of these have been developed to support families in their caretaking role so that children can remain in their own communities rather than be admitted to state institutions. A family of a child with a disability is entitled outright to some of these programs (eg, schools); others are on a first-come, first-served basis (eg, respite waiver funds). These latter programs are likely to have longer waiting lists, and access is often made difficult by layers of bureaucratic red tape. Programs differ from state to state in terms of quantity and quality of services and eligibility criteria. Additionally, policies and regulations change rapidly. The various formal supports include:

1. *Educational Supports.* Due to the passage of Part H of PL 99-457 in 1986 (later refined and clarified in PL 102-119, the Individuals with Disabilities Education Act [IDEA] of 1991), all states have early intervention programs serving infants and toddlers

with developmental delays and/or known disabilities. Eligibility criteria vary. It is important that physicians be aware of this entitlement program and that they make timely and appropriate referrals. Once the child is enrolled, the physician can serve as a team member in the development and implementation of an Individualized Family Service Plan (IFSP). The AAP has advocated for a strong physician role in these early intervention programs.<sup>12</sup>

Public schools are mandated by IDEA to provide individualized educational services to CSHCN. Schools must also provide "related services" (ie, nursing services and/or physical, occupational, and speech therapies) when they are necessary to facilitate the child's education. Medicaid funds may be used to provide medical support services for technology-dependent children in the school setting. When a child is diagnosed with a serious disability that would usually necessitate residential placement, "non-educational funds" may be available through the school for respite and recreational services to support parents in their caretaking roles, theoretically preventing institutionalization. Parents must request these services during the child's annual educational planning meeting and ensure that they are written into the child's individual education plan.

2. *Financial Supports.* Although there are many financial resources available to help subsidize support programs, they are often not advertised. Parents must search and, when resources are found, the parents must comply with a complicated eligibility process that is usually bogged down with bureaucratic red tape. Long waiting lists are not uncommon; therefore, it is important that parents put their child's name on these lists as early as possible. The assistance programs are administered through local offices of state or federal agencies.

*Supplemental Security Income (SSI)* is a federally funded income maintenance program designed to provide monthly cash benefits to support citizens of any age with disabilities. Eligibility depends on a disability severity criterion for the individuals and an income and asset criterion for the family. SSI criteria and benefits have been changing dramatically over the past few years.<sup>13-15</sup> The newest law requires a child to have a "medically determinable physical or mental impairment which results in marked and severe functional limitations." The requirement for a "marked and severe" limitation has eliminated many children who met previous criteria. Currently, many children, especially those with attention deficit hyperactivity disorder, have been flagged for re-evaluation or for cessation of benefits.

*Medical Assistance (Medicaid and Medicare)* provides broad coverage for medically necessary services, including home care services, to individuals with financial need. The child who is eligible for SSI benefits is almost always financially eligible for Medicaid, but the application process is separate and must be

conducted through a state-run agency. For most children, losing SSI benefits based on the new law discussed previously will also mean losing Medicaid. The family should contact the state agency that manages Medicaid benefits. This is usually the Department of Public Welfare or the Department of Medical Assistance.

*The Tax Equity and Fiscal Responsibility Act (TEFRA)* provides a mechanism for children with disabilities to qualify for medical assistance based on their own income and assets, not those of their parents. A monthly copayment, based on family income, may be required. In some states, this program is known as the Katie Becket Waiver. This is not a federally mandated program, and eligibility and funding are changing dramatically. Even when waiver programs exist, they are often underfunded, which results in families competing for a limited number of available benefits.

*Title V Children with Special Health Care Needs programs* offer care to some families who are financially ineligible for Medicaid yet lack adequate health insurance coverage. States differ tremendously in how the funds are applied, and, for the most part, they have supported a narrow spectrum of programs for orthopedic, cardiac, and other surgical conditions.

*Long-Term Financial Planning:* The usual "simple will" leaving property to CSHCN in a conventional trust may not be in the child's best interests.<sup>16</sup> Conventional approaches that encumber the child with assets may at the same time disqualify him or her from receiving federal support for services. When a child with a disability receives an inheritance, government agencies providing benefits to the child may charge the child for services rendered—current and past services. An inheritance could be quickly exhausted. If the trust has been established for the siblings as well, their shares may be equally at risk. A "supplemental trust" (sometimes called the "special needs will") may be an appropriate solution. The language of the trust must clearly identify the intent of the parent. For example:

The express purpose of this trust is to provide for John Doe Jr's extra and supplemental care, maintenance, support, and education in addition to and over and above the benefits John Doe Jr otherwise receives as a result of his disability from any local, state, or federal government or from any private agencies, any of which provides services or benefits to persons with disabilities. It is the express purpose of the grantor to use the trust estate only to supplement other benefits received by the beneficiary.

Directing parents toward sound financial or legal advice before they establish a will or trust can be invaluable. For more information, contact the National Institute on Life Planning for Persons with Disabilities at 800-854-3343.

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**3. Personal Assistance Programs.** With the recent movement to recognize the rights of persons with disabilities and discourage institutionalization has come an expansion of services designed to promote family unity and inclusion in the community by supporting parents in their caretaking roles. Personal care attendant (PCA) services are available through various agencies and depend on the severity of the child's condition and the family's income and circumstances. A needs assessment is done to determine the number of hours of assistance for which the child qualifies. The family may use any portion of those hours to get in-home help from an assigned individual who is generically trained in providing care to the disabled. The theoretical availability and the reality of finding and retaining some of these services can be distressingly discrepant (Saumweber P, personal communication, 1994). The cost savings to the government in supported home care versus hospital or institutional care for technology-dependent children is enormous, as one would have predicted.<sup>17</sup> In truth, however, this savings is attributable to the amount of uncompensated nursing care provided by family members. For access to and additional details on these types of programs, the family must contact the state or county offices for the Departments of Human Services, Public Health, or Mental Health and Mental Retardation.

**4. Physical Supports.** Enacted in 1990, the ADA not only prohibits discrimination against people with disabilities, it proactively imposes responsibilities on members of society to allow access. The ADA legislates unparalleled freedom and opportunity for disabled people.<sup>18</sup> Public and private transportation systems must be accessible to all individuals. Architectural barriers, within reason, must be removed from all public places, and new facilities should be constructed barrier-free. Essentially all public accommodations and places—from airports to zoos—must be readily accessible, again within reason. Philosophically, it emphasizes that people with disabilities are "people first" and have access to all aspects of society. For more information, contact the Disability Access Office typically located in the Department of Planning in city governments or call

the national ADA Information Line (800-514-0301) or visit their website at <http://www.usdoj.gov>.

## CONCLUSION

Most families with CSHCN need some degree of community support to help them raise their children at home, and often they look to their pediatrician for help in both identifying and accessing these resources. In many instances, physicians can provide guidance to families in initiating the support-finding process by referring a parent to one or two of the following five agencies:

1. The local Parent Training and Information Center (PTIC)
2. The United Cerebral Palsy or ARC affiliate
3. The local public school special education or Part H-EIP coordinator
4. The municipal or county health and human services departments
5. The local United Way

Physicians who care for children should keep these five or six telephone numbers readily available. It is also helpful for physicians to develop a personal contact in each of these agencies. Additionally, the annual *EP Resource Guide* will come in handy for national and state contacts for many services and products about which parents commonly inquire. What the parent really needs is an insider—someone who knows what is available in the community, how to access it, and whether it is any good. Parent support and advocacy groups can provide this valuable service to physicians and families in terms of identifying the best resources.

Keep looking and digging. The resources are out there.<sup>19</sup>

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