

The Health Care of Children and Youths With Disabilities

Council on Scientific Affairs, American Medical Association

Nearly 2 million adolescents between ages 10 and 18 years have a chronic condition associated with limited activity. Reflecting the interaction between functional ability and socioeconomic influences, an adolescent living in poverty and those with parents with less than a ninth-grade education are almost twice as likely to be disabled as other adolescents. Most children with disabilities have a regular source of health care. These young people and their families, however, may face major financial problems and are often in need of protection from excessive out-of-pocket expenses. This issue becomes more prominent during late adolescence as youths leave the home setting, become financially independent, marry, or transfer from a pediatric to an adult health care system. Treating children and youths with disabilities necessitates cooperation among physicians, schools, community agencies, and families. Although not necessarily a problem for family physicians, an additional challenge for pediatricians is helping adolescents make the transition from the pediatric to the adult health care system. As the survival rate of children with disabilities increases, pediatricians are faced more frequently with having to prepare their adolescent patients and their families for transfer to adult care providers.

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Nearly 2 million adolescents, or 6.2% of children aged 10 to 18, have a chronic condition associated with limited activity.¹ These conditions include:

- Mental disorders (32%), including psychiatric disorders, mental retardation, and substance abuse.
- Diseases of the respiratory system (21%), including asthma and bronchitis.
- Diseases of the musculoskeletal and connective systems (15%), including arthritis and acquired limb deformities.
- Diseases of the nervous system (6%), including multiple sclerosis, cerebral palsy, and epilepsy.
- Diseases of the ear (4%), including hearing impairment.
- Other conditions (22%), including

speech and vision impairment, cardiovascular disorders, and endocrine disorders.

Reflecting the interaction between functional ability and socioeconomic influences, adolescents living in poverty and those with parents who have less than a ninth-grade education are almost twice as likely to be disabled as adolescents living in more socioeconomically advantaged families.¹

The impact of a chronic condition can be measured by the ability to perform usual daily activities. Almost 60% of disabilities result in limitation of the kind or amount of major adolescent activity, such as school or work.¹ These adolescents attend special education or are able to attend school or work only part time. Thirty-two percent of disabilities result in a limitation in other, less major activities, such as participation in sports, and 8% result in the adolescent being unable to participate in either school or work.

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Adolescents with special health care needs experience four times more "restricted-activity" days per year (26.9 days vs 7.7 days) and three times more days in bed (12.2 days vs 3.7 days) than other adolescents.

Most children with disabilities have a regular source of health care. From a five-state survey of special education classes, it was learned that 74% of disabled children had a physician and an additional 19% had another place from which they received regular health care.² This figure varied somewhat by the type of disability: 92% of children with a high-prevalence disability (eg, emotional problems) vs 97.5% of those with a low-prevalence disability (eg, Down syndrome, deafness, and cerebral palsy) had a regular source of health care. Children with a low-prevalence disability were also more likely to receive care from a physician (87% vs 72%) and to have had a specialty care visit during the last year (35% vs 11%).

These young people and their families may face major financial problems regarding payment of medical services and often need protection from excessive out-of-pocket expenses. The cost for hospitalization and outpatient

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care of children and adolescents with disabilities was estimated to be \$2.9 billion in 1980.³ One survey⁴ found that families with disabled children paid out-of-pocket health expenses ranging from \$870 to \$10 299 per year, compared with \$270 per year for families without a disabled child. Adolescents with special health care needs have somewhat lower rates of private health insurance coverage than other adolescents (66% vs 75%), and they are more likely to have a public source of insurance (19% vs 9%).¹ However, adolescents with disabilities are just as likely to be uninsured as nondisabled adolescents (13.8% vs 14.1%).¹ When asked why they lacked health insurance, 83% of families responded that insurance is either too expensive or their coverage was terminated due to

loss of job. Private insurance clauses excluding preexisting conditions constitute another barrier to care. This issue becomes more prominent during late adolescence as youths leave the home setting, become financially independent, marry, or transfer to the adult health care system.

EARLY IDENTIFICATION OF DISABLING CONDITIONS

Opportunities for identifying potentially handicapping conditions are based on several factors, including age and type of disability. Of disabled children in special education programs, approximately 4% are identified as disabled at birth; 16%, between birth and age 2½ years; 29%, between ages 2½ and 5 years; and almost 50%, between ages 5 and 7 years.⁵ Viewed from another perspective, the health care system is the predominant place in which disabilities are identified in children from birth to age 2½ years, the preschool setting is where disabilities are identified in children between ages 2½ and 5 years, and schools are the main setting for identifying older children. Regarding type of disability, 85% of low-prevalence disabilities (eg, Down syndrome, cerebral palsy, mental retardation, visual and hearing disorders, and neurologic disorders) are identified before age 5 years.⁵ Low-prevalence disabilities are more likely to be diagnosed by a physician than by a nonphysician. In distinction, approximately 80% of high-prevalence disabilities (eg, speech disorders, hyperactivity, emotional problems, learning disabilities, and other developmental disorders) are identified after age 5 years, usually by a teacher or other school professional. Children with more complex problems are identified earlier than those with less complex difficulties.

To promote early identification and intervention and improve the health of children with disabilities, Congress enacted the Education for All Handicapped Children Act (PL 94-142) in 1977. This law mandated that public health departments and schools work to identify all handicapped children in the community and provide them with educational services. The original law was amended to expand the opportunities for identification and intervention and is now known as the Individuals With Disabil-

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ities Act 1990 (PL 99-457). Major features of the new law include the following⁶:

- Programs for children with disabilities must be available for individuals aged 3 through 21 years.
- New incentives for the development of programs for handicapped children identified from birth to age 2 years. Incentives for the development of programs for children older than age 2 years are continued in the new bill.
- Incentives for other agencies to develop infant intervention programs.
- A mandate for the development of individual educational plans for all students with disabilities and individual family service plans for handicapped infants from birth to age 2 years.
- Increased attention to family needs and family involvement.

PHYSICIANS, SCHOOLS, AND FAMILIES

Because of the difficulty multiproblem children have in navigating through the complex health, social service, and education systems, parents have become vocal about their desire to participate as partners in the care of their disabled children. Responding to the need for greater family involvement, then Surgeon General C. Everett Koop several years ago called on physicians and other health professionals to reframe their approach to children with special health care needs. Koop called for health care that is family centered, community based, coordinated, and culturally competent. The basic tenets in this approach are that families, physicians, and schools should work together to (1) achieve a better understanding by parents and professionals of the disability, how to cope with that disability, and the physical, psychologic, and social effects on the child and family, (2) operate as partners in the identification, provision, and receipt of appropriate services, and (3) improve the availability and accessibility of community-based services.⁷

Family-centered, community-based care calls on physicians to not only provide traditional management of acute and chronic medical conditions, but also to work with families, schools, and other community agencies.⁸ Various workbooks and educational materials have been developed to prepare physicians to care for children with disabilities.⁸⁻¹¹ Working with schools to ensure that each disabled child receives appropriate health services and educational opportunities presents a major challenge for physicians. These efforts take a substantial amount of time, and service may not always be reimbursable.

Although 93% of parents in a survey of children attending special education classes reported that their child had a regular source of health care, only 14% of physicians in the community were found to have had contact with that school.² Physician contact with the school had been made for 9% of children with a high-prevalence disability and for 38% of those with a low-prevalence disability. Rarely (for less than 2% of students), however, did a physician

actually visit the school to help with the development of the individual education plans. The need for better communication between school personnel and physicians is demonstrated by the results of one study in which researchers found that only 52% of special education teachers stated they understood the long-term consequences of children's health conditions and, of those who taught children who received medications, only 30% were aware of the potential pharmacologic side effects of the medications.²

Although not necessarily a problem for family physicians, pediatricians face the challenge of helping adolescents make the transition from the pediatric to the adult health care system. As the survival rate of children with disabilities increases, pediatricians and pediatric-based programs are faced more frequently with having to turn over patients' care to providers who care for adults. Without

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appropriate preparation for adolescents and their families and for the involvement of adult health providers, this process could result in some adolescents not continuing the health care they need. The transition to the adult health care system requires coordination between the medical providers of each system, knowledge by the adolescents and their families regarding the reasons behind the transition, and a clear understanding by adolescents and their parents regarding the mechanism of transfer and the way in which the new system works.

RECOMMENDATIONS

The Council on Scientific Affairs recommends that the American Medical Association do the following:

1. Inform physicians of the special health care needs of children and youths with disabilities.
2. Encourage physicians to pay special attention during the preschool physical examination to identify physical, emotional, or developmental disabilities that have not been previously noted.
3. Encourage physicians to provide services to children and youths with disabilities that are family centered, community based, and coordinated among the various individual providers and programs serving the child.
4. Encourage physicians to provide schools with medical information to ensure that children and youths with disabilities receive appropriate school health services.
5. Encourage pediatricians to establish formal transition programs or activities that help adolescents with disabilities and their families plan and make the transition to the adult medical care system.
6. Inform physicians of available educational resources, such as the National Center for Youth With Dis-

abilities, the National Center for Networking Community Based Services, local resources, and various manuals that help prepare them to provide family-centered health care.

7. Encourage physicians to make their offices accessible to patients with disabilities, especially when doing office construction and renovations.

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This report was presented at the December 1991 meeting of the American Medical Association House of Delegates as Report J of the Council on Scientific Affairs. The recommendations were adopted as amended in lieu of resolution 49 (I-90), and the remainder of the report was filed.

This report is not intended to be construed as or to serve as a standard of medical care. Standards of medical care are determined based on all of the facts and circumstances involved in an individual case and are subject to change as scientific knowledge and technology advance and patterns of practice evolve. This report reflects the scientific literature as of December 1991.

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