

AMERICAN ACADEMY OF PEDIATRICS

Transition of Care Provided for Adolescents With Special Health Care Needs

Committee on Children With Disabilities and Committee on Adolescence

ABSTRACT. This policy statement describes how the pediatrician can work closely with patients with special health care needs and their families as an advocate and educator to help them adapt positively to an adult-focused system of health care. Issues in health care transitions including independence and dependence, education and vocational issues, insurance issues and limitations, Social Security, and hospitalization are outlined.

Families with children with chronic illness, cognitive or sensory impairment, physical disabilities, and/or other special health care needs often face a particularly difficult transition from adolescent to adult health care.

BACKGROUND

During the past two decades, the survival rates associated with most chronic illnesses have improved greatly such that more than 90% of children with a chronic illness and/or disability now survive to adulthood.¹

Improved understanding of prevention and treatment (including better nutrition, anti-inflammatory and antimicrobial agents, enzyme replacement therapy, and earlier multidisciplinary interventions for many conditions) has resulted in successful therapeutic interventions that diminish long-term or secondary disability and improve long-term function. For example, children and adults who require mechanical ventilation or oxygen therapy not only survive but also can attend school and obtain employment. Societal changes now encourage more children and adults with substantial cognitive and/or physical impairments to live at home or in community settings with appropriate support.²

Most chronically ill and/or disabled individuals want to live full, productive lives. Pediatricians can play a critical role in reinforcing positive attitudes and beliefs while helping adolescents and their families to make appropriate transitions to adult health care. Some young adults will require ongoing medical care for chronic health conditions (eg, diabetes,

arthritis, and severe asthma), whereas others may require technological assistance (eg, ventilation, specialized wheelchairs, or communication devices) or personal care attendants. Still others, especially those young adults with primarily developmental disabilities, may need only supported living assistance (eg, specialized housing or supportive employment).

The pediatrician (or other health care providers who may be providing a medical home for children and adolescents with disabilities) should play a central role in helping adolescents and their families make the transition to adult health care. Toward this end, the pediatrician needs to know which practitioners in the community have the clinical skills needed and an interest in working with adults with disabilities.

Under some circumstances, young adults with special health care needs may choose to continue with their current health care supervision because some pediatricians comfortable with adult health and sexuality issues can provide adult-oriented medical care if the patient and family agree. Criteria and timing for eventual transitions will vary.

ISSUES IN HEALTH CARE TRANSITIONS

Most adolescents with chronic conditions require coordinated care that frequently involves multiple health care providers. Coordination and access may be more difficult when adolescents reach adulthood; often, an entirely new group of health care providers assume responsibility for adult patients. These providers may be unfamiliar with the patients' histories and the priorities and concerns of these patients and their families.³

Also, adolescents with special health care needs may need to adjust to the possible loss of a close and longstanding relationship with their pediatrician and other specialists when transferring to adult health care. This change may be difficult, because many pediatricians often work with multidisciplinary teams while adult-oriented health care providers tend to focus more on specific system-oriented complaints and rely on independent consultants for further specialty care. Because many adult health care providers receive only limited training regarding adolescent or young adult disorders associated with disabilities and transitional issues, the provider may be unfamiliar with the disabling condition (eg, cystic fibrosis or spina bifida) and its management.

Schidlow and Fiel have summarized other major

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The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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obstacles to smooth transitions from adolescent to adult health care. The severity of the illness or disability, the level of maturity, acceptance and understanding of the patient, additional environmental or family stresses, the need for control by parents or health care provider, a distorted perception (by parents or health care provider) of potential patient outcomes, and lack of patient or family support systems all may contribute to transition stress.

Independence and Dependence

The goal for all children is to move progressively from complete dependence toward independence. Children with disabilities, regardless of cause, should be encouraged to develop the highest possible level of independence based on a realistic and objective evaluation of their abilities and limitations. The adolescent and the family may be unsure of the benefits of greater independence or even unaware of the patient's ability to achieve partial or total independence.⁴

The typically healthy desire for independence may be misconstrued by some adolescents with diabetes as license to avoid administering insulin regularly but may help the youth with cerebral palsy who, despite parental or physician protests, decides to use a wheelchair instead of crutches to participate with peers more actively.

For adolescents who are more dependent on others for a variety of care needs, the acquisition of some of the skills needed for self-care and independent living can contribute to a more successful and comfortable life at home or preparation for group homes or other adult living arrangements. This learning promotes self-esteem and facilitates more full participation in their community. Toward this end, the person with a disability should have the opportunity to acquire skills to understand and to develop a sense of financial responsibility when appropriate.

The development of skills for independent living (such as living alone or in assisted-living accommodations, planning or preparing meals, or grocery shopping) frequently requires assistance from multiple disciplines. The pediatrician can assist in the planning process by informing the patient, family, and others involved in training about the patient's special health care needs, and by providing clear and specific recommendations regarding the abilities of the patient and the possible need to alter the environment.

Education and Vocational Issues

Most adolescents with disabilities have participated in modified educational programs. Frequent and prolonged hospitalizations or illness convalescence can interrupt continuity or delay the achievement of educational goals. Many well-intentioned programs offer limited opportunities for experiences outside the school and may fail to prepare the adolescent for many life experiences and the world of work and independent living.⁵

Preparation for vocational assessment and training should not be postponed until the student is 18 to 21 years old because training may be prolonged for the adolescent with a disability. The pediatrician can

assist the adolescent, family, and school to understand the medical aspects of the student's condition and seek an appropriate person to coordinate the evaluation and transition to higher education or vocational training.⁶⁻⁸

The pediatrician should be aware that the nationwide federal/state vocational rehabilitation program has an agency in each state capital as well as other local offices. These locations can be found in the telephone directory (under the state listing for Rehabilitative Services or Vocational Rehabilitation Services.) These agencies assist eligible people with disabilities to define a suitable employment goal, assist with additional educational opportunities, and assist with employment. Supported or sheltered employment options provide opportunities that can enhance the quality of life and personal satisfaction of young people with severe disabilities.⁹ The Americans With Disabilities Act also has the potential to help with issues of access to job opportunities and public facilities.¹⁰

Insurance Issues and Limitations

Adolescents with chronic illnesses and disabilities face special problems regarding access to health insurance, especially when they are no longer covered by their parents' insurance.^{11,12} Currently, insurance provisions regarding preexisting medical conditions may limit or even preclude insurance eligibility for many. Insurance coverage for therapies important to the disabled person's mobility, communication, or physical and psychological functioning often are not provided or provided only for a very limited number of hours per year if they are covered.

The adolescent or young adult with disabilities often requires insurance that covers a broad range of services, including multiple medical specialty consultations, laboratory tests, equipment, and prescription plans.¹³ Such insurance rarely is available to many workers with disabilities which may limit their productivity on the job or the types of jobs for which they are qualified, forcing them to accept lower-wage employment that may not offer insurance or provide the types of benefits needed at an affordable cost.

Social Security

The Social Security Administration directs two programs of financial assistance to eligible persons during the transition process.^{14,15}

First, the Supplemental Security Income program provides cash benefits for low-income persons who are blind or have other disabilities. Recent Supplemental Security Income changes help children and those younger than 18 years with disabilities to qualify for benefits. Persons older than 18 years are eligible to receive monthly payments if they have little or no income or resources (eg, a savings account) and have a substantial disability.

Second, the Social Security Disability Income considers the employment status of the applicant's parents. "Benefits are paid to persons who become disabled before age 22 if at least one of their parents had worked a certain amount of time under Social Security but now is disabled, retired, and/or deceased."

Recent legislation has made major changes in both programs to encourage people with disabilities receiving these benefits to work and to become independent. Also, certain provisions of Supplemental Security Income allow for the maintenance of Medicaid coverage even when the young adult becomes employed.¹⁶

Information is available through the local Social Security office or by calling the Social Security Administration toll free at 1-800-772-1213 (voice) or 1-800-325-0778 (TDD).

Hospitalization

Young adults with a chronic disease or special health care needs may require frequent hospitalization, just as they did during childhood. As they mature, many develop ambivalent feelings regarding hospitalization, particularly when they become the oldest patients in the pediatric or adolescent unit. At the same time, however, their familiarity and comfort with the unit personnel, policies, and procedures may make them reluctant to enter an adult unit.

Inpatient care should be a part of the short- and long-term planning for management of the adolescent and young adult with special health care needs. Hospitalization may be an essential or infrequent adjunct to a health care program but still is subject to issues of transition and planning. Preferably, arrangements for hospital care should not be made on an urgent or emergent basis but planned well in advance with attention to detail.

The individual plan for hospitalization should consider whether the adolescent or young adult prefers admission to an adolescent or adult unit. It is important that the unit staff receive training in the management of those long-term conditions that arise during childhood or adolescence. When pediatricians continue to provide primary care for young adult patients, they should seek admitting privileges to the adult unit to ensure their continuing participation as the primary attending physician or as a consultant.

SUMMARY AND RECOMMENDATIONS

Technical advances and improved care for children with chronic diseases have allowed most children with chronic disabilities to reach adulthood. Planning is essential to achieve appropriate transition from pediatric health care to adult health care. Transition planning should:

- begin early, with special attention to maximizing opportunities for independence and for the necessary health, educational, and social services;
- include active participation of the family and patient in the process;
- consider the patient individually, realistically, and positively, encouraging functional independence and appropriate attitudes toward self-worth and interpersonal relationships (including issues of sexuality);
- encourage the patient's willingness or ability to accept the plan;
- consider having the pediatrician and the adult

health care practitioner as comanagers for a period of time (eg, 1 or 2 years); and include recommendations by the pediatrician for referral to adult health care providers (especially subspecialists) who are sensitive to and have an interest in families that include adults with special health care needs.

The pediatrician should participate actively in the above process and become aware of local, state, and national resources for family and patient assistance (eg, Vocational Rehabilitation Services and Social Security Administration) and, if necessary, help patients and their families gain access to the appropriate agencies or information.

Above all, the pediatrician should work closely with patients and their families as advocate and educator to help them adapt positively to an adult-focused system of health care.

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