

AMERICAN ACADEMY OF PEDIATRICS

Committee on Children With Disabilities

The Role of the Pediatrician in Transitioning Children and Adolescents With Developmental Disabilities and Chronic Illnesses From School to Work or College

ABSTRACT. The role of the pediatrician in transitioning children with disabilities and chronic illnesses from school to work or college is to provide anticipatory guidance and to promote self-advocacy and self-determination. Knowledge of the provisions of the key federal laws affecting vocational education is essential for the pediatrician's successful advocacy for patients.

ABBREVIATIONS. IEP, individual education plan; IDEA, Individuals with Disabilities Education Act.

Children with developmental disabilities enter adolescence with a unique set of strengths and needs and family expectations about their academic or work career. The term "transition," used in the context of adolescence, refers to the movement of children from pediatric, or child-centered care, to adult health services and the economic and social responsibilities of adult life. Transition planning must be included as part of the annual individual education plan (IEP) for all students receiving special education services from age 14 until graduation. The Individuals with Disabilities Education Act (IDEA) Amendments of 1997 mandated that transition planning be included as part of developing a student's annual IEP. The IDEA specifies that IEP teams base these transition plans on student desires and preferences for a preferred adult lifestyle in the following areas: career/employment, community living, recreation/leisure, relationships, transportation, and community integration or involvement. Current "best practice" for transition planning promotes student self-determination by using a curriculum specifically designed to teach self-determination skills and student leadership (when possible) of IEP/transition meetings.

Students and their parents are often asked to choose between pursuing a standards-based academic program potentially leading to a diploma or a vocational-based program focused on gaining experience and life skills related to and necessary for employment. This latter choice leads to a certificate of completion rather than a standard high school diploma. This choice may be problematic for students with mild disabilities who want a standard

high school diploma yet also want some vocational classes in their curriculum.

Students who do poorly in general academic courses are more likely to drop out of high school than are students who are experiencing success in secondary school vocational programs. However, there are many college students today with developmental disabilities (visually impaired, physically impaired, hearing impaired) who, with consistent support in primary and secondary education, are successful college students.

A vocational-technical education can assist many students with developmental disabilities and chronic illnesses to become independent and productive members of society. According to findings of the National Longitudinal Transition Study of Special Education Students,¹ students with disabilities who are enrolled in vocational-technical education:

- stay in school longer;
- have better attendance;
- attend postsecondary vocational education; and
- are more likely to have a job 2 years later.

Public Law 101-392, the Carl D. Perkins Vocational and Applied Technology Education Act of 1990, defined vocational education as:

*"Organized education programs offering a sequence of courses which are directly related to the preparation of individuals in paid or unpaid employment in current or emerging occupations requiring other than a baccalaureate or advanced degree. Such programs shall include competency-based applied learning, which contributes to an individual's academic knowledge, higher order reasoning, and problem-solving skills, work attitudes, general employability skills, and occupational-specific skills necessary for economic independence and a productive and contributing member of society."*²

This broad definition of vocational education promotes active and cooperative learning for students, yet also is responsive to the needs of business and industry. For children and adolescents to gain the most from prevocational and vocational programs, parents, educators, pediatricians, businesses, and members of the community must work with students to plan programs that lead to a productive life.

Career exploration begins in preschool and kindergarten by visiting places of work (ie, fire station, grocery store, police station) and lasts through adult education. It is essential that students with disabilities understand the world of work, have realistic expectations of job demands, and are exposed to a wide range of businesses. Interventions that assist

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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with career exploration and self-assessment include the following:

- identifying successful role models;
- encouraging students to volunteer;
- arranging for internships or “shadowing” experiences;
- encouraging students to work during the summer; and
- conducting student tours of industry and business, especially where there are role models at work.²

Three pieces of federal legislation greatly benefit the vocational preparation and employment of students with disabilities. The IDEA of 1990 reaffirms the national effort to provide an equitable general education for students with disabilities. The IDEA mandates that transition planning for special education students begins no later than age 14 and is documented on students’ IEPs. The student should be present and involved in the IEP conference. Unless there are cognitive and/or judgmental limitations that preclude it, it is also important for the teenager to participate in drivers’ education to have mobility within the community. Exploring options for driving in the educational setting is possible; however, a more involved driver’s evaluation in a rehabilitation setting may be necessary if special modifications to the car or van are necessary to make driving possible. The rehabilitation counselor is an advocate of the student’s IEP. This planning must list interagency links and responsibilities for each team member, the student and parents, and the school and other service agencies involved in assisting the student attain the transition outcomes.

Section 504 of the Rehabilitation Act of 1973 allows children with special needs who are ineligible for IDEA to receive personal and assistive technology interventions, supported employment, and streamlined transition from high school into rehabilitation programs. Children eligible for the services under Section 504 must have a physical or mental impairment that limits 1 or more major life activities.

The Americans with Disabilities Act of 1990 guarantees equal employment opportunities and requires employers to make reasonable accommodations for employees with disabilities. Through guaranteed access and accommodation, these federal laws have secured educational, personal, and transition services for students with special needs and have expanded transition opportunities. Pediatricians, as advocates for students with developmental disabilities and chronic illnesses, should be aware of this pertinent landmark legislation.

MEDICAL ROLE AND RECOMMENDATIONS

Lifelong planning is appropriate for children and adolescents with developmental disabilities and chronic illnesses. However, services provided to these children tend to be delivered by different professionals for different age groups—infancy, preschool, youth, adulthood, and older persons. Particular attention should be given by the pediatrician to

promoting continuity during periods of transition. Young adults with special health care needs and their parents expect advice from their pediatricians on when and how to transfer to the care of an internist or family physician. A personal telephone call by the pediatrician to the primary care physician is appropriate to facilitate the transition. A written summary of the pertinent medical history, surgery, therapies, medications, and immunizations received facilitates successful transition and is a key step in care coordination.

Transition in adolescence to adulthood is the movement from child-centered to adult-oriented activities.^{3,4} This process depends on early education and coordination of efforts by all persons involved. The major areas of transition include moving from: 1) child- and family-centered pediatric care to adult-oriented medical care, 2) the school environment to the workplace, and 3) living at home to community living. The journey from childhood to adulthood is characterized by starts and stops, anxiety and anger, and hope and despair, coupled with an ever-increasing mastery of an essential set of life skills necessary for independence. For youths with developmental disabilities or chronic illnesses, the adolescent process of exploring limits, reality testing, and self-image development may be severely delayed. The childhood of teenagers with special health care needs has often created an ever greater dependence on their parents and other adults. Thus, the pediatrician is in an excellent position to lead the process of educating parents and their children with special health care needs with developmentally appropriate anticipatory guidance to foster independence beginning soon after the initial diagnosis. The cornerstone of this continuous anticipatory guidance is to promote habits of good health, to encourage activities that promote responsibility and self-reliance, and to teach where and when to ask for help. Thus, the pediatrician is the professional well-positioned to have a continuous and coordinating role in promoting the development of skills, knowledge, and attitudes essential for successful transition from school into adulthood.

All pediatricians should ensure through collaboration with local schools that their patients with disabilities or chronic illnesses have access to the following:

1. A medical home that promotes accessible, continuous, comprehensive, family-centered, coordinated, and compassionate care. To be most effective, the medical home must be a partner in the partnership among the family, teenager, and other community health and human services professionals.⁵
2. Assessment of child’s strengths and abilities, **not only disabilities**. Students must understand and appreciate their abilities, interests, and values. They need to have high self-esteem, know their career options, and be able to make good decisions. To make all this happen, the transition process must be ongoing and embedded in the curriculum in the students’ early years with ca-

reer exploration and progressing through IEP/transition planning.

3. Planning for transition services begins at age 14 years as part of the annual IEP. Encourage the family to actively participate in IEP/transition planning.
4. Printed information about the provisions in IDEA designed to promote the identification and achievement of appropriate transition outcomes and names and telephone numbers of community-based resources to help families fully understand and maximize the potential of the process for their child. Someone knowledgeable about legal rights of persons with disabilities should review entitlements with the family and teenager, including Supplemental Security Income and Medicaid.
5. An opportunity with parental and adolescent consent for sharing pertinent medical information with the IEP team. The pediatrician should explain the modifications that may be necessary based on the student's personal medical history.
6. Enrollment as early as possible in the state's rehabilitation counseling services.
7. Opportunities to explore a variety of careers through part-time jobs, volunteer work, or guidance with mentors.³
8. Transfer by the family to the teen opportunities to take responsibility for self-care, budgeting of a weekly allowance, and household and yard chores consistent with physical and mental abilities.³
9. Contact with successful young adult role models.
10. Attendant care services, if needed, while the teenager is still living at home. Allow the teenager to interview prospective attendants and then to select, hire, and supervise the employee³ with parental input if the teenager is still a minor.
11. A resource list of local independent living arrangements. Support the enrollment of the teenager in an independent living skills course as soon as age requirements are met.
12. An experienced family counselor who can assist the parents and teenager in defining boundaries and responsibilities if substantial parent-teenager conflict exists.³
13. Meaningful employment opportunities in the community and vocational education that challenges the student and prepares the student for the 21st century.
14. A primary clinician who is a good listener for open discussion of the teenager's career goals and concerns.

CONCLUSION

The transition from childhood to adulthood is a prolonged, variable process in children with special health care needs. Prevocational counseling begins in early childhood or at the time of diagnosis. Special education and vocational education are strengthened when there are strong ongoing family-professional

partnerships. Federal legislation and current educational best practices shape and guide the vocational assessment process and transition outcomes. The pediatrician can bring many strengths to this transition process, including a longitudinal relationship with the family that offers multiple opportunities for providing anticipatory guidance and constructive interventions.^{6,7}

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