

Primary Care for Adolescents with Developmental Disabilities



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KEYWORDS

- Developmental disability • Intellectual disability • Interdisciplinary care • Transition
- Youth with special health care needs • Adolescent health • Primary care

KEY POINTS

- Disability is not a trait or characteristic, but a lack of ability to participate fully in society because of the interaction between a persons' functional limitations and the social and physical environment.
- The Americans with Disabilities Act requires health care professionals to ensure access to health care.
- To assist with transition planning, speech, occupational therapy, physical therapy, and neuropsychiatric assessments can help determine strengths and challenges.
- Communication is a basic right that can be enhanced with adaptive technology, support, and appropriate examination room etiquette.

INTRODUCTION

Definition of Developmental Disability

Disability is the inability to exert control and choice over one's life, and to fully participate in and contribute to community. The ability of people to participate fully depends on the interaction between their functional limitations and the social and physical environment in which they live. Environments can be more or less enabling. For example, a student with a learning disability can access the general curriculum if the room has few distractions and the teacher explains instructions verbally. The same student might fail to achieve their potential without those accommodations. Reducing disability can be achieved through improving function or through better adapting the social and physical environment. A developmental disability is a disability that is present during the developmental period when the brain is forming. Because the disability is present during the developmental period, the experience usually shapes part of that person's identity.

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There are no specific traits or characteristics that define developmental disability. All people are mixtures of strengths and weaknesses. However, administrative definitions of developmental disability have been developed to define who is eligible for services and supports. Administrative definitions are often based on criteria that describe functional limitations. Other administrative definitions rely on diagnostic labels such as autism, cerebral palsy, and epilepsy. These conditions are not always disabling. People with those diagnoses have a wide range of functional abilities (**Box 1**). More information and resources on care for people with developmental disabilities are available on the Office of Developmental Primary Care websites: <http://odpc.ucsf.edu>.

Barriers to Accessing Care

Barriers to accessing health care can be physical, financial, or programmatic.^{2,3} Physical barriers to medical care include waiting rooms and examination rooms that cannot accommodate wheelchairs and caregivers; bathrooms that are not accessible; or examination tables, scales, or diagnostic equipment that is not fully accessible. Appropriate equipment is needed to ensure physical accessibility, especially when children become too heavy to lift. Many medical practices do not meet the minimum standards for accessibility under the Americans with Disabilities Act. The US Department of Justice has issued guidelines for access to medical care for individuals with mobility disabilities.⁴ During adolescence, to facilitate care, people with physical disabilities may also need assessment for home modifications.

Although the Affordable Care Act will reduce financial barriers to care for adolescents with disabilities, many families caring for children with disabilities struggle financially.⁵ Families living in states with higher income inequality have higher family financial burdens for funding the health care of children with special health care needs.⁶

Box 1

Federal definition of developmental disability

According to the Developmental Disabilities Assistance and Bill of Rights Act of 2000, a developmental disability is a severe, chronic disability of an individual that:

1. Is attributable to a mental or physical impairment or combination of mental and physical impairments
2. Is manifested before the individual attains the age of 22 years
3. Is likely to continue indefinitely
4. Results in substantial functional limitations in 3 or more of the following areas of major life activity:
 5. Self-care
 6. Receptive and expressive language
 7. Learning
 8. Mobility
 9. Self-direction
 10. Capacity for independent living
 11. Economic self-sufficiency
12. Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated¹

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