

Achieving Independence

Case:

A 15 year old male with Spina Bifida is being seen in clinic for his school physical. He uses a wheelchair and has an appropriately sized wheelchair. He has had some difficulties this year with urinary tract infections but since skills of in-and-out catheterization have been reinforced he has been free of infections. Otherwise he is healthy and his exam reveals no new findings. He does well in school. When asked about post secondary education plans, he tells you he is unsure what he would like to do in the future. On further questioning, he tells you that he enjoys math and would like to “do something with math.”

You wrap up with session by asking if there are any questions or concerns and the patient and his families indicate there are no outstanding issues.

After the patient and his stepfather leaves the room to head to the car his mother stops you and expresses concerns about her son’s ability to support himself when he becomes an adult.

Questions:

1. Are most adults with disabilities unemployed? What are some of the barriers to employment for individuals with disabilities?
2. Does his mother have the right to request the school to help develop a plan for post-secondary employment?
3. Does the Americans with Disabilities Act (ADA) play a role in helping adolescents and adults in the workforce? Do you think that this child will be able to become gainfully employed as an adult?
4. For adults with disabilities who are unable to work are there federal programs to provide financial assistance?
5. Should pediatricians discuss transition of medical care to adult providers with adolescents and their families? Do pediatricians often discuss transition of care with their patients?
6. What are the key components for defining disability?
7. Are most children with special health care needs insured? Is the insurance adequate?

Achieving Independence

Facilitator's Guide:

1. *Are most adults with disabilities unemployed? What are some of the barriers to employment for individuals with disabilities?*

In 2000, 81% of adults without disability were employed while only 32% of those with disabilities were employedⁱ. These numbers are consistent with 2003 Department of Labor and Census data.

Delineating the barriers to employment for those with disabilities is a difficult task but factors that contribute include the following: lack of transportation, inadequate training, lack of appropriate jobs, concerns about losing access to federal and state services, and individual and familial misconceptions about the ability of persons with disabilities to enter the work forceⁱⁱ.

2. *Does his mother have the right to request the school to help develop a plan for post-secondary employment?*

In the 2004 reauthorization of the IDEA, Congress wrote: The federal government has an ongoing obligation to support activities that contribute to positive results for children with disabilities, allowing those children to lead productive and independent adult lives (PL 108-446). To this end, children with disabilities are afforded the opportunity to achieve their goals through a formalized process in their Individual Education Plan (IEP). The plan for transitioning adolescents into adulthood under the IDEA is generally referred to as “transition services.”

Transition services under the IDEA is a coordinated set of activities that:

- Is designed as a results oriented process that promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated services, independent living, or community participation
- Is based on the individual student's needs, taking into account the student's preference and interest
- Includes the following: instruction, related services, community experiences, development of employment and other post-school adult living objectives, and acquisition of daily living skills and functional vocational evaluation.

Specifically, the IDEA requires transition objectives to be met by the age of 14 and 16. By age 14, all IEPs must begin to include the student's post school goals and appropriate transition services should be identified. By age 16, the needed transition services must be implemented.

Unlike special education services, there is no central system for identifying adult services once students leave the school environment. Therefore, parents, pediatricians, and the adolescents must work together early to identify community resources that will help the

Achieving Independence

adolescent achieve his or her goals. For this reason, the transition plan is a vital component of the IEP.

3. Does the Americans with Disabilities Act (ADA) play a role in helping adolescents and adults in the workforce? Do you think that this child will be able to become gainfully employed as an adult?

The Americans with Disabilities Act (ADA) is a civil rights legislation that protects individuals with disabilities against discrimination. The ADA covers access to employment, state and local government programs, access to places of public accommodations, transportation, and telecommunications. While there are five titles of the ADA, Title I protects individuals with disabilities from employment discrimination. It is an important piece of legislation both for adolescents who are seeking employment and for parents of children with disabilities who are working to ensure their child's participation in the community as adults.

Title I of the ADA applies to any qualified job applicants or employees with a disability who: (1) has a physical or mental impairment that substantially limits one or more life activities; or (2) has a record of such impairment; or (3) is regarded as having such an impairment.

Title I of the ADA requires employers to make reasonable accommodations for known disabilities of a qualified applicant or employee. If an accommodation for an employee imposes undue hardship on the employer, it is not necessary to provide the accommodation. Examples of reasonable accommodations include: making worksites physically accessible, modifying work schedule, restructuring jobs, providing interpreters, or making assistive devices available.

4. For adults with disabilities who are unable to work are there federal programs to provide financial assistance?

Children with disabilities may be eligible for income administered by the Social Security Administration (SSA). In February 2007, one million children were receiving SSI payments that averaged \$550 per month. To be eligible for SSI, children must meet a specific definition of disability and their family's income must be below a certain threshold.

For disability purposes in the SSI program, a child becomes an adult at age 18 and different medical and nonmedical rules are employed in deciding who is eligible for the program. For example, only the adult's income and resources are used to determine financial eligibility and there is a different definition for disability. If the child who turns 18 is already receiving SSI, he or she must reapply for continuation of benefits as an adult and is subject to the new terms. If as a child they were not eligible for SSI because the family's income was too high, he or she may become eligible for SSI age 18.

Achieving Independence

5. Should pediatricians discuss transition of medical care to adult providers with adolescents and their families? Do pediatricians often discuss transition of care with their patients?

Transition of care from pediatric care to adult care is an important step because it helps the adolescent focus not only on their health, but also other aspects of life, including post-secondary education, employment, and independent living. While this transition is important to all adolescents, it is especially important for children with special health care needs because of their greater needs and barriers to successful transitions.

Geenenⁱⁱⁱ, et al. identified potential areas that the pediatrician can assist in transitioning care and studied the current practices of pediatricians in facilitating transitioning. The identified areas for pediatrician support of transitioning include the following:

- Understanding how an adolescent's health condition or disability may affect employment or postsecondary education
- Helping an adolescent develop the knowledge and skills necessary to communicate with others about his or her condition and needed accommodations
- Helping the adolescent to identify necessary accommodations
- Coordinating with other professionals around the adolescent's
- Parents clearly look to pediatricians to help assist in the transition of their child to adulthood.

Geenan, et al. quantified the importance to parents of transition activities. Their study consisted of a questionnaire to parents of children between the ages of 13 and 21 who experienced a physical, developmental, behavioral/emotional, learning, or health-related disability. Parents were asked to report on a 5 point Likert scale the importance a various topics that a pediatrician could participate. Means are based on responses to the Likert scale that ranged from 1 ("not at all") to 5 ("very important").

Geenan's results are as follows:

Mean Parent Importance Ratings for Transition Activities

Rank	Activity	Mean (SD)
1	Talking care of my child's general health	4.63 (0.77)
2	Taking care of my child's disability	4.52 (.89)
3	Coordinating my child's health with other health professionals	4.30 (1.12)
4	Help my child get health insurance	4.12 (1.43)
5	Help me find a health care provider when my child becomes an adult	4.12 (1.41)
6	Teaching my child to manage own health	4.08 (1.40)
7	Working with the school to coordinate care	4.03 (1.34)
8	Discussing with my child how to take care of his or her health to be successful at work	3.97 (1.44)
9	Connecting my child to other services in the community	3.94 (1.38)
10	Screening my child for mental health problems	3.77 (1.48)

Achieving Independence

11	Talking to my child about drugs and alcohol	3.61 (1.58)
12	Talking to my child about sexual issues	3.49 (1.52)
13	Helping my child apply for or keep Social Security income	3.12 (1.81)

Source: Geenen, et al. *Journal of Adolescent Health*, Vol. 32, No. 3

The CDC recently published the results of the National Survey of Children with Special Health Care Needs, 2005-2006^{iv}. The survey was conducted as a telephone interview and included roughly 40,000 children with special healthcare needs. Key findings of the report related to this case discussion are listed below.

Activity	Percent Responding “yes”
Doctors have discussed shift to adult provider	42%
Doctors have discussed future health care needs	62%
Doctors have discussed future insurance needs	34%
The child receives anticipatory guidance in the transition to adulthood	38%

Source: CDC, National Survey of Children with Special Health Care Needs, 2005-2006

6. What are the key components for defining disability?

Interestingly, there is no single definition for disability. In the past categorical definitions (i.e. defining disability by the medical diagnosis like Autism, Spina Bifida, Cerebral Palsy) was the norm but definitions that relate to function and service needs are increasingly becoming more common. Today, different programs define disability differently. This is important to families because eligibility for services is dependent on meeting established definitions. Examples of definitions employed by different programs are provided below:

- **Social Security Income (SSI)^v**

The child must have a physical or mental condition that results in marked or severe functional limitations. The condition is expected to last 12 months or can be expected to result in death. This definition applies to children up to the age of 18. For children 18 or older, the adult definition of disability applies.

The adult SSI definition for disability is as follows: The individual has a medically determinable physical or mental impairment which results in inability to do any substantial gainful activity. The condition is expected to last 12 months or can be expected to result in death.

- **Individuals with Disabilities Education Act (IDEA)^{vi}:**

For children ages birth until 2 years old: Infants and toddlers with disabilities are defined as children who need early intervention services because they are experiencing developmental delays, as measured by diagnostic instruments and procedures, or have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.

Achieving Independence

For children ages 3 until 21: The IDEA lists 13 different disability categories under which 3 through 21-year-olds may be eligible for services. For a child to be eligible for services, the disability must affect the child’s educational performance. The disability categories listed in IDEA are: autism, deaf-blindness, emotional disturbance, hearing impairment (including deafness), mental retardation, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, or visual impairment (including blindness).

- Title V- Maternal and Child Health Block Grant^{vii}

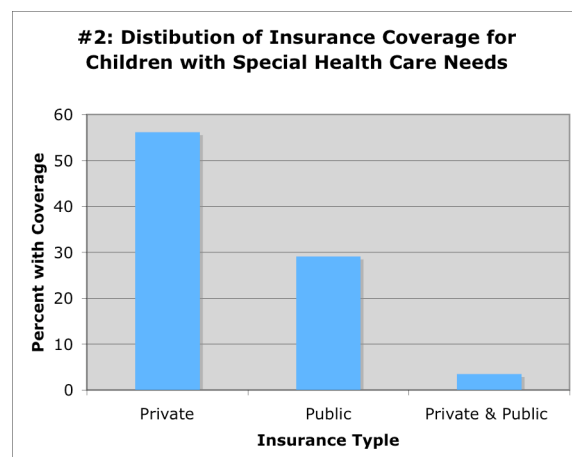
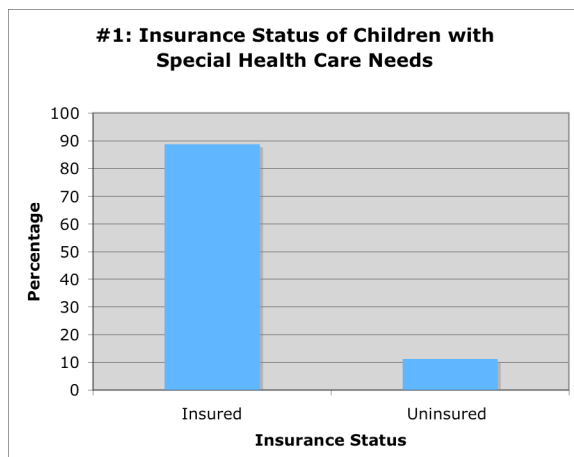
This program uses the term “children with special health care needs” and defines these children as follows: Children with a risk or at risk for a chronic physical, environmental, behavioral or emotional condition that requires health and related services beyond that required by children generally.

- Americans with Disability Act (ADA)^{viii}

An individual with a disability is someone who has a physical or mental impairment that substantially limits one or more major life activities and has a record of such impairment or is regarded as having such impairment.

7. Are most children with special health care needs insured? Is the insurance adequate?

Children with Special Health Care Needs are an especially vulnerable population and access to regular insurance is important to maximize their health outcomes. Paul Newacheck^{ix} looked at children with special health care needs and their insurance status by type. In the Newacheck study, private insurance included all forms of private insurance while public insurance included Medicaid, Medicare, military and other public assistance programs. He found the following results in a sample of children with special health care needs: Approximately 88.8% of children with special health care needs have health insurance (See Graph #1). Of those with health insurance, 56.2% have private health insurance (graph #2).



Achieving Independence

Source: Newacheck, P, et al. "Access to Health Care for Children with Special Health Care Needs." Pediatrics: 2000; 105: 760-766.

While being insured is an important determinant for ensuring healthcare needs are met, insurance does not guarantee that needs will be met. In an attempt to characterize the care delivered to children with special health care needs, the CDC's National Survey of Children with Special Health Care Needs, 2005-2006^x, included relevant questions. Below are representative results:

Activity	Percent Responding "yes"
Insurance usually or always meets the child's needs	87%
Costs not covered by insurance are usually or always reasonable	72%
Insurance usually or always permits child to see needed providers	90%
Child has received routine preventative care in the last year	77%

Source: CDC, National Survey of Children with Special Health Care Needs, 2005-2006

ⁱ Lou Harris and Associates, Inc. NOD/Harris survey of people with disabilities Washington, DC: Lou Harris and Associates, 2000.

ⁱⁱ Loperst, Pamela. "Barriers and Supports for Work Among Adults with Disabilities: Results from the NHIS-D". Urban Institute, January 2002.

ⁱⁱⁱ Geenen, et al. "Understanding the Role of Health Care Providers During Transition of Adolescents with Disabilities and Special Health Care Needs. Journal of Adolescent Health. 2003: Vol. 32, No. 3

^{iv} Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs, 2005-06

^v Social Security Administration. "Understanding SSI Eligibility Requirements," 2008. Accessed on June 22, 2008 at: <http://www.ssa.gov/ssi/text-eligibility-ussi.htm>

^{vi} National Dissemination Center for Children with Disabilities. Disabilities That Qualify Infants, Toddlers, Children and Youth for Services Under the IDEA, 2002. Accessed on June 20, 2008 at: <http://www.nichcy.org/pubs/genresc/gr3.htm>

^{vii} McPherson, et al. "A New Definition of Children with Special Health Care Needs." Pediatrics. 1998; 102:137-139.

^{viii} Jones, Nancy. The Americans with Disabilities Act: The Definition of Disability. CRS Report for Congress, March 9, 2006.

^{ix} Newacheck, P, et al. "Access to Health Care for Children with Special Health Care Needs." Pediatrics: 2000; 105: 760-766.

^x Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs, 2005-06