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Synopsis

Disability is a natural part of the human experience. In order to maximize potential, adolescents with disabilities require multidisciplinary transition planning and life-skill training. Health care professionals can help reduce barriers to accessing health care. They can encourage self-determination and connect patients to self-advocacy organizations. They can facilitate smooth transitions to adult health care services by writing comprehensive summaries; communicating directly with receiving doctors; remaining available for consultation; and by planning transitions in stages. Careful descriptions of a patient's baseline traits and function are critical. This not only assists in person-centered planning processes, but ensures that new caregivers and health professionals have the information they need to recognize changes in function or behavior that can signal illness.

Key Points:

- Disability is not a trait or characteristic, but a lack of ability to fully participate in society due to 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 exam 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 for a person to participate fully is dependent on the interaction between a person's 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 a person's identity.

There are no specific traits or characteristics that define "developmental disability." All people are a mixture 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 ability.

List 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—

- i. is attributable to a mental or physical impairment or combination of mental and physical impairments;
- ii. is manifested before the individual attains age 22;
- iii. is likely to continue indefinitely;
- iv. results in substantial functional limitations in 3 or more of the following areas of major life activity:
 - v. Self-care.
 - vi. Receptive and expressive language.
 - vii. Learning.
 - viii. Mobility.
 - ix. Self-direction.
 - x. Capacity for independent living.
 - xi. Economic self-sufficiency; and
 - xii. 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 coordinated.¹

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 exam rooms that cannot accommodate wheelchairs and caregivers, bathrooms that are not accessible, or exam 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 U.S. 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.

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

Programmatic barriers to care include lack of sign language interpreters or print materials available in alternative formats, and inadequate appointment length. Programmatic barriers also include lack of training for clinicians and a lack of care coordination. Barriers to care can be reduced through the development of primary care practices that meet the characteristics of patient centered medical homes.⁷ Such practices emphasize coordination with specialty care as well as school based services, government and community agencies, and adult specialists.^{8, 9}

Interdisciplinary team

Health care for people with developmental disabilities requires interdisciplinary, team-based care. While parents play a central role in their children's care, the role of parents must shift as children reach adolescence. Reaching adolescence should prompt a review of the team membership, roles and structure. For adolescents who have the capacity to assume more responsibility for managing their own health care needs, a plan should be developed to gradually transfer responsibility from parent to child. Free, online training is available for patients and physicians at <http://www.healthytransitionsny.org/>.¹⁰ This resource includes videos to model appropriate exam room etiquette and communication about transition topics.

For those who will continue to require support, parents may intend to continue to be involved in their child's care after their children become adults. However, most children will outlive their parents' capacity to provide support. Therefore it is important for patients to learn to direct and receive some of their support from personal assistants, other family members, friends and supporters. This broadens the circle of support, the number of people with knowledge and expertise about the patient's medical care, and enables the patient to develop healthy independence.

Transition to health care providers who serve adults is best accomplished gradually. Pediatric doctors can ensure a smooth transition by developing a medical summary, calling receiving doctors and making themselves available for consultation or to co-manage care for a period of time.

Exam room etiquette

Patients and caregivers are the best sources of information about etiquette. The table below provides some general guidelines. More information can be found on the Office of Developmental Primary Care website:<http://odpc.ucsf.edu..>

List 2: Exam Room Etiquette

Assume competence

Ask how your patient communicates best

Speak directly to your patient with a normal adult tone

Wait quietly and expectantly for a response

Don't pretend to understand; check for understanding

Treat assistive devices as personal space

Ask before assisting

Identify yourself to people with visual impairments

Respect privacy

Ensure access to health care

Assessment

Diagnostic assessment

In preparation for transition planning, consider repeat diagnostic evaluations and assessments. The field of genetics is rapidly evolving. If the patient has dysmorphic features

suggestive of a genetic condition, and doesn't have a diagnosis or a recent evaluation, a referral for genetic consultation is indicated. There is a range in how genetic traits are expressed in individuals. Genetics alone do not determine a person's potential. Likewise diagnostic labels do not describe an individual's strengths, aspirations or abilities. Genetic and diagnostic information can help connect patients, caregivers and clinicians to information and support. It can help clinicians identify risks for associated medical problems.

Also, consider repeat physical, speech and occupational therapy assessments at least every few years. Separate speech assessments may be required for dysphagia and for communication. Neuropsychological, educational and vocational testing may also be beneficial. Repeating assessments that were done at younger ages is important because some patients improve due to learning adaptive skills, medical interventions or maturity. This can lead to fewer functional limitations. Others may lose function due to neurodegenerative conditions, injury, arthritis, medical complications, chronic stress or medication side effects. For patients in the special education system, some of this testing may be requested through the school system. Copies of these assessments should be placed in the medical chart. They are critically important descriptions of the patient's baseline function. Without that information, it can be very difficult to make diagnoses in the future such as dementia or a slow decline in range of motion or mobility. In addition to school assessments which are focused on helping students access the general curriculum, consider independent assessments that explore a broader range of life and adaptive skills.

Table 1: Documentation of baseline function:

	Domain	Notes
Cognitive	language, literacy, financial management, sense of time, self-direction, memory, attention, learning style, problem solving, ability to follow rules, abstraction, social skills and naiveté	Include special education or neuropsychiatric assessments.
Neuromuscular	gait, movement disorder, tone, posture, range of motion, swallow, fine and gross motor control	Patients or physicians can take video footage for documentation. Physical therapists, occupational therapists, speech therapists, neurologists and orthopedists can do detailed assessments if needed.
Seizure	seizure type, length and frequency	Any stereotyped behavior or emotion lasting less than three minutes can be seizure
Sensory	hearing and vision testing; sensory integration and processing; sensitivity to lights, sounds, smells, touch, or foods	Note the patient's typical behaviors when in pain and tips for gaining cooperation with physical exam.

Mental health/behavior	disposition; regulating and triggering stimuli; signs of distress; mental health diagnoses	Note strategies for preventing and managing meltdowns or shutdowns and improving cooperation
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Developing Strengths

By the time people are adolescents, the developmental trajectory is usually clearer than it is in young children. While the focus of early intervention is often remediating deficits, it is important to recognize that all people also have strengths. Equal emphasis should be on identifying and developing areas of relative strength. All people need opportunities to develop loving relationships, learn new skills and make a contribution to their family and community. Adolescents need experiences of success. They also need opportunities to try, fail and be exposed to the natural consequences.

Adaptive Behavior

Assessments should focus on the conceptual, social and practical skills that people use in everyday life. Practical skills should include basic and instrumental activities of daily living for work, partnering with health care professionals and personal care staff, decision making, stress management, using transportation, keeping routines and schedules, managing money and using technology and adaptive equipment.¹¹

Communication

The right to communicate is fundamental and it is the foundation of effective patient care. All people communicate and all behavior is communication. Adolescents can be non-verbal, have speech that is hard to understand or periodically lose speech. They may benefit from adaptive equipment such as voice output devices, letter boards, visual supports or alternative communication strategies. If this has not been thoroughly explored, it is important to do so while school resources are available to support it.

For clinicians who wish to improve their skills, short video clips modeling communication with non-verbal patients are available via iColleague in the MedEd Portal under “Mock Clinical Interviews with Nonverbal Standardized Patients”.

<https://www.mededportal.org/icollaborative/resource/904>.

Establishing Goals of Care

Even when healthy, adolescents with developmental disabilities have traits and characteristics that fall outside of the statistical norm. Each person has their own balance, even if it is very atypical. Strategies to help people be more compliant, behave more normally or function more independently are not always the best strategies to help patients achieve their own potential. Sometimes people with disabilities thrive when they find alternative ways to function, interdependent relationships, and when they accept help. Accepting help with weaknesses or deficits can allow more energy to develop strengths and special interests. For example, a person may be able to walk, but keep up with their friends better and have less pain

when they use a wheelchair. Another may prefer to take an extra class in computer science than to spend elective time in speech therapy to work on producing clearer speech.

Adolescents can define for themselves what strategies work best for them, and their own goals and priorities.

Transition Planning (patient centered)

The American Academy of Pediatrics, American Academy of Family Physicians and American College of Physicians have developed protocols and guidance for planning health care transitions.¹² The process starts at age 12-13 and continues until the transition to an adult-focused medical system is complete.¹³ Transferring care to adult oriented clinicians is a process rather than an event, and should involve preparation and communication.

Medical Summary

Transferring key medical and educational records is critical. For people with complex disabilities, by the time they reach adulthood, their records are often too voluminous to be of clinical use. A key component of the transition process is the development of a comprehensive medical summary by the primary care doctor who knows the patient best. In addition to detailed information about baseline function, this summary should include information about the patient's support services, education and care providers with contact information. It should also include information about all therapeutic trials. It is important to include the ones that were successful and ones that failed. This information can be critical to diagnosing new

symptoms in the future, especially if the patient is unable to give a comprehensive history, and family is no longer available to supplement it.

Health Passport

A health passport is a portable record developed and maintained by the patient and caregiver with key clinical and care information. It is important information for caregivers and clinicians. A health passport includes information regarding: communication, power of attorney or supporters, diagnoses, medications, allergies and tips for care.

List 3: Tips for care can include:

- how to administer medications
- feeding plans
- calming strategies
- methods to help cope with procedures
- clues for recognizing pain
- instructions for transfer or assisting with mobility
- dressing
- assisting with hygiene
- avoiding sensitivities
- ways to prevent boredom
- ways to facilitate follow up

Documentation

For adolescents with cognitive or communication disabilities, caregivers play a critical role in recognizing illness, reporting signs and symptoms and monitoring and implementing health care plans. Parents usually recognize when their children are not functioning at their baseline. Paid caregivers are less familiar with the patient, and therefore may not. When the child is diagnosed, parents typically receive training in how to support their children with disabilities. When case workers, professional caregivers or other relatives assume responsibility, they also need training. Also, as adolescents spend less time with parents, important signs and symptoms can go unrecognized. Documentation systems need to be created to track vital signs, weight, bowel movements, seizures, food intake, menstruation, blood sugars, medication administration and behaviors. Forms for this purpose as well as other resources are available on the website of the Office of Developmental Primary Care <http://odpc.ucsf.edu>. Caregivers need clear protocols for when to call a doctor for any change in behavior or function. As adolescents develop more independence from parents, some may assume more responsibility for maintaining documentation.

Maximizing social environment

All people thrive in environments where they are accepted as valued members of the community, and when their communication is acknowledged and supported. It is important to avoid dehumanizing language that suggests that the lives of people with disabilities are less meaningful or that they are less capable of directing their lives or making an important contribution. Words such as unfortunate, suffering, burden, tragic, dependent, and bound

suggest that people with disability inherently have a poor quality of life and lack agency.¹⁴

Praising someone for being brave or inspirational merely for being disabled is also a form of low expectations.

Sometimes parents have difficulty accepting their child's disability. Clinicians can help keep the focus on practical problem solving. Physicians can help parents to appreciate their children by celebrating personal accomplishments, helping to interpret behavior positively and developmentally and modeling comfortable, respectful communication. Any discussion of a child's challenges can start with a review of their strengths. It is also helpful to assess the unmet needs of parents and other caregivers. Parents can be encouraged to pursue their own relationships and interests, and can be referred to resources for respite so they can attend to their own wellbeing. More information on cultural competence when working with people with disabilities can be found on the Office of Developmental Primary Care website:

<http://.odpc.ucsf.edu>.

Maximizing physical environment

Most people are familiar with adaptations to the built environment for people with mobility disorders. These include things like ramps, automatic doors and curb cuts. However, other aspects of the physical environment also impact function. For example, helpful environmental supports include signage and other visual supports, lists, instructions, calendars; emergency signals; organization of the physical space and reduction of visual distractions. The sensory environment can also be more or less enabling. Many people have sensitivities to

scents, and certain types of lighting and sounds. Reducing high contrast lighting, strobes, alarms, Televisions, and fluorescents can make a medical environment more comfortable.

Improving Function-Building Life Skills

Adolescents with developmental disabilities may need to be explicitly taught life skills that other children acquire without specific instruction. Functional life-skill training is often neglected in more academically-oriented special education. However, these skills can be as important for successful adulthood as earning an academic degree. Children enrolled in special education services are entitled to receive services until they receive a diploma or until age 22. If included in an individualized education program, special educators can help prepare adolescents for adult life or can help parents develop a life skills training program.¹⁵ Components of a comprehensive training plan are listed in table 4.

List 4: Developing strengths

- Academic skills
- Activities of daily living
- Assistive and Adaptive Devices
- Communication
- Functional life skills
- Healthy lifestyle
- Self-Advocacy
- Self-care

Social skills

Vocational skills

Self-determination:

Adolescents with disabilities should be supported to participate in meetings where issues that concern them are addressed. They should also be educated about citizenship and their right to vote. A transition plan can include voter registration. Since people with disabilities are disproportionately affected by government policy decisions, it is important to exercise their right to participate in the political process. Self Advocates Becoming Empowered has a tool kit for providing this education for people with cognitive disabilities.¹⁶ Participation in youth leadership and self-advocacy activities can help build these critical skills.¹⁷

Also, adolescents should participate in informed consent decisions. Capacity to make an informed consent decision should be assessed for each decision. Capacity can fluctuate. Not all decisions require the same cognitive ability. Informed consent requires a person to understand the options, the risks and benefits of each, weigh them against each other and communicate a choice. Patients should receive support such as plain language explanations, pictures, videos, or demonstrations. Many people who do not have the capacity to make a specific decision, can still contribute information about values and priorities. These should be considered. Some people who do not have capacity to make an informed consent decision do have the capacity to select someone to serve as Power of Attorney.

Prevention of abuse and neglect

People with disabilities need skills to resist and protest, lest they become easy targets for abuse. This is important regardless of the adolescent's support needs or functional limitations. For people with cognitive and communication challenges, it is important to teach students a method for communicating when they are being mistreated. Adolescents with disabilities should be encouraged to set boundaries; make choices; and spend time alone with peers and away from parents, teachers and other authority figures. Clinicians should inquire about abuse and neglect during appointments, and be alert to the possibility when a patient is having difficulty. For any suspected or reported abuse, the accused should be separated from the patient during the investigation. All complaints should be followed up.

Bullying

Bullying of people with disabilities is more common than the general population.¹⁸ The U.S. Department of Education finds that bullying of a student with a disability that results in the student not receiving meaningful education benefits constitutes a denial of their right to a free, appropriate public education. Schools are directed to take a variety of actions to address and prevent bullying.¹⁹ If students use communication aids, vocabulary about bullying should be included. It is also important to teach and support students to set personal boundaries including retaining control of assistive devices, maintaining personal space and limiting touch.

Isolation/Seclusion

Peers can bully, but so can parents, teachers, caregivers, and professionals. Bullying from authority figures can include isolation and seclusion, exclusion, aversive therapies, physical or chemical restraint, medical neglect and derogatory language.

Navigating Puberty

Changing Roles

As a patient nears age 18, HIPAA releases and an advanced directive or health care Power of Attorney should be discussed. To ensure continuity, it is helpful to have these conversations prior to the age of majority. Guardianship and Conservatorship are legal proceedings available in most states for people who have cognitive disabilities. They are often unnecessary if supports are in place to support decision-making and/or if the patient has a valid Power of Attorney for health care and Representative Payee or financial trustee to assist with finances. Clinicians can provide paperwork for a health care Power of Attorney. For more complete planning, referrals can be made to case workers and estate lawyers with expertise in disability.

Family Adjustment: Acceptance

When children are young, their developmental trajectory is often unclear. Some parents go through a process of grieving for a child they hoped for and did not have. Others pursue treatments they hope will lead to a cure. Parents are often unaware of how

expressing their disappointment about missed expectations can impact the self-esteem of their children. Even non-verbal children are sensitive to these messages from their parents. Focusing on deficits and weaknesses can distract from appreciating the positive qualities of their children, and their unique perspective and experience. Clinicians can help by pointing out growth, progress, accomplishments and positive characteristics, and by taking the time to genuinely enjoy our interactions with our patients. Clinicians can refer parents to their local Parent Training and Information Center for support: <http://www.parentcenterhub.org/find-your-center/>. Like all adolescents, youth with disabilities benefit from opportunities to make a contribution to family and community through chores, volunteer work or employment.

Sexuality

People with disabilities can and often do have sex. Individual Education Programs can include goals for health and sexuality education. Many adolescents with cognitive disabilities benefit from explicit education about the unwritten social rules of negotiating sexual relationships.²⁰ Youth also need explicit explanations of the laws and social rules of sexual activity. Adolescents with disabilities who require support to access medical care still need confidential care. Like all adolescents, privacy and confidentiality are critical for discussions of gender and sexual identity, sexuality, prevention of sexually transmitted infection and pregnancy.

Rates of sexual abuse are high in the population. People with disabilities are often taught to comply with authority. However, youth also need skills to protest and resist authority when appropriate. This is an important skill to prevent and identify abuse.

Accessing Service Systems

Some patients needs have been met primarily by the school district or other programs accessible to children, but not to adults. If the patient is or will become eligible for public benefits or programs, it is helpful to start the process of applying for these programs early. This will help avoid disruption in needed services. Families are often unprepared for the drop off in the level of support they receive that usually accompanies graduation from school.

Person-centered planning

Person-centered planning is an ongoing process of helping people with disabilities plan for their future. Person-centered planning is a team process where people come together to support a person with a disability to develop relationships, participate in community and increase their control over their life. It is a structured planning process that starts with a personal profile, shares visions for the future and develops plans, services and supports to achieve the goals. Many tools to structure this process are available on line.²¹ Person-centered planning teams benefit from a case coordinator or social worker with expertise in public health insurance programs, Department of Rehabilitation, Department of Developmental Services, Department of Housing and Urban Development and Social Security programs.

Monitoring health and safety

Care management

Many adolescents with disabilities benefit from care management services. These services are sometimes available through the state Department of Developmental Services, Patient Centered Medical Homes or health plans. Parents typically do a lot to coordinate care for their children, but still benefit from working with people with expertise in transition planning.

Circles of Support

Circles of support are informal support networks such as family, friends and community members who share responsibility for access, inclusion and support of a disabled person. Adolescence is a good time to discuss expanding and engaging circles of support. Siblings sometimes take on a greater role in providing support.

Crisis Intervention

Families can become overwhelmed with the needs of adolescents in crisis. For adolescents with challenging behavior, parents may need access to respite or crisis homes, training in behavior modification techniques, or assistance with diagnosing the cause of the patient's distress. Unrecognized medical problems and pain are a common cause of challenging behavior. Physicians should maintain lists of local resources. To find local resources, every state has federally funded parent centers that offer training information and assistance to families of children with disabilities.²²

Estate Planning

Parents may want to consult an estate attorney with expertise in disability. Giving or leaving money to support a child with a disability can inadvertently make them ineligible for government programs their children need. With careful financial planning, even small amounts of financial support can improve the lives of people with disabilities. Organizations such as the Special Needs Alliance and the Arc of the United States can provide guidance to families developing plans for long term care.^{23, 24}

Summary

Helping adolescents with disabilities to develop the skills and supports to direct their own lives will ensure better quality of life in adulthood. Wellness is more than being free of illness; it is being in balance, participating, and being included in all aspects of life. Health professionals have a lot of influence over the lives of people with developmental disabilities. We have a key role in helping people access to medical care and adaptive technology. We also have a role in determining access to education, employment, transportation, housing, services, supports, assistive equipment, adaptive technology and public benefits. In many situations we have a key role in ensuring the opportunity for our patients to make decisions and form and maintain relationships. Systematic assessment and planning processes can improve quality of life as adolescents transition from child to adult oriented services.

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