

Health Care for Adults with Disabilities*

TIPS FOR PRIMARY CARE PHYSICIANS AND NURSES

Why is health care an issue?

Adults with intellectual or other developmental disabilities often face barriers to good health care. Many primary care providers do not have much experience treating individuals with intellectual and developmental disabilities (IDD).

There may be physical barriers to receiving care, such as examining tables that don't lower completely for those in wheelchairs. Or individuals may have problems finding transportation. Some individuals have difficulties explaining their symptoms or expressing pain, so determining the presence of an illness or injury can be more difficult. Preventive care and health promotion is often not targeted to this group of individuals.

Many adults with developmental disabilities have complex or difficult-to-treat medical conditions. They may require multiple medications. They are also at higher risk of behavioral and mental health concerns.

They may also face financial issues, since many adults with developmental disabilities are unable to find employment or are underemployed.

This tip sheet will explain ways that medical professionals can better care for people with developmental disabilities.

People with disabilities are people first

- They want to be treated with kindness and respect.
- If they are ill, they want to feel better.
- They don't want to wait, and they may be less tolerant of waiting than other patients.
- They want continuity of care.
- In essence, they want the same kinds of things other patients want.

Some patients may need accommodations, such as:

- A physically accessible office and accessible medical equipment
- Varied methods of communicating, e.g., using the person's augmentative communication device, using visual aids, demonstrating what you're going to do, or just using simple, concrete language



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- A quiet room without fluorescent lights
- Additional time for the appointment to allow for establishing rapport, explaining procedures or transferring to/from a wheelchair
- Removing items from waiting rooms or examining rooms that could be eaten, for the safety of those with pica

Key information to gather early

- Will the patient or caregiver be able to give an accurate medical history?
- If the patient has communication difficulties, how does the patient indicate pain or report symptoms?
- Is the patient capable of giving informed consent?
- Does the patient need accommodations? If so, what type?
- Does the patient have or want a caregiver to accompany him/her and stay during the visit?
- Does the patient have a diagnosis related to his/her disability and does he/she have additional physical or mental health conditions?

An important note

Individuals with developmental disabilities are 4 to 10 times more likely to be victims of crime than those without disabilities. Abuse and neglect often go unreported because individuals are either unable to report or unwilling to report for fear of losing needed

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support or their place to live. Research has found, among adults, as many as 83% of females and 32% of males are the victims of sexual assault in their lives. If you suspect abuse, neglect, or exploitation of a person with a disability, you should report it to the Tennessee Department of Human Services at 1-888-APS-TENN, or to the appropriate agency in your state.

Vanderbilt Kennedy Center

The **Vanderbilt Kennedy Center** (VKC) works with and for people with disabilities and their family members, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be a University Center for Excellence in Developmental Disabilities, a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center, and a Leadership Education in Neurodevelopmental and Related Disabilities Training Program.

IDD Toolkit www.iddtoolkit.org

The IDD Toolkit website offers health care information for primary care physicians and nurses to provide improved care to adults with intellectual and developmental disabilities. Checklists and disability-specific tables may help guide medical treatments and preventive care. Sections address informed consent and behavioral and mental health concerns, including crisis management and prevention. With funding from the WITF Foundation, Palo Alto, CA, the IDD Toolkit was adapted for U.S. use based on *Tools for the Primary Care of People with Developmental Disabilities* (Surrey Place, 2011).

Tennessee Disability Pathfinder

Tennessee Disability Pathfinder is a free statewide phone, web, and print referral service in English and Spanish. It connects the Tennessee disability community with service providers and resources. Its website database has over 3,000 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC, TN Council on Developmental Disabilities, TN Department of Health, and the TN Department of Intellectual and Developmental Disabilities. Contact www.familypathfinder.org, (615) 322-8529, toll-free (800) 640-4636.

Other Resources

- **Case-based modules on health of people with intellectual disabilities**

These question-and-answer modules are designed to teach more about the adult phase of health and health care for people with developmental and intellectual disabilities, including common health issues for adults with ID; socio-cultural influences on health of adults with ID; and self-determination and person-centered care as essential elements of health promotion and healthcare.

www.iddhealthtraining.org

- **Easy-to-read health materials**

The Florida Center for Inclusive Communities offers a series of factsheets and materials that are aimed at helping patients with IDD understand their health care needs. <http://flfcic.fmhi.usf.edu/program-areas/health.html>

- **Moving Into Adult Health Care: What Do Primary Health Care Providers Need To Know?**

This booklet offers ways physicians can help young adults with disabilities make the transition from pediatrician to adult care. http://portal.ct.gov/-/media/Departments-and-Agencies/DPH/family_health/children_and_youth/pdf/PrimaryCareNeedtoKnowpdf.pdf?la=en

- **Physician education in developmental disabilities**

This free, 12 credit-hour webinar series is designed to enhance the practice skills of primary care physicians and residents who would like to provide better care to their adult patients with developmental disabilities. Developed by the American Academy of Developmental Medicine and the Florida Developmental Disabilities Council. <https://aadmd.org/page/pedd-webinar-series>

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