

Scheduling an Appointment

Moving from Pediatric to Adult Health Care

Continuing Education Module



healthytransitionsny.org

✓ Learn ✓ See ✓ Do

Skills for Moving from Pediatric to Adult Health Care

- Scheduling an Appointment
- Getting Health Insurance
- Deciding About Guardianship
- Speaking up at the Doctor's Office
- Understanding Your Disability
- Managing Medications
- Keeping a Health Summary
- Looking into Service Coordination
- Setting Health Goals
- Finding Community Resources

Welcome!

This education module provides information that families and professionals can use to help youths who have developmental disabilities to schedule an appointment.

Scheduling an Appointment:

Skill attainment for this topic is defined when the adolescent or young adult is able to:

- ✓ Differentiate between a routine visit and a visit for a specific reason
- ✓ Organize insurance card, agenda/calendar and other information necessary for scheduling an appointment
- ✓ Request accommodations (if needed) when calling to schedule an appointment
- ✓ Accurately record time and date of appointment (written or recorded by scribe)
- ✓ Understand that the scheduling of an appointment is incomplete until arrangements for transportation have been made as well

This continuing education module is part of a 10-unit curriculum that was developed for families, health care providers, service coordinators and other professionals who would like to facilitate the transition from pediatric to adult health care for youths who have developmental disabilities. Adolescence and young adulthood is a time of tremendous change, not just physically, but also in terms of social and emotional development, and due to transitions in services, supports and health care providers. The Healthy Transitions curriculum provides a context for mutual understanding and collaboration during this complex time.

The curriculum is organized around 10 key skills that youths need to develop in order to transition to adult health care. The skills are not sequential. They can be developed over time, between the ages of 14-25 years. The Healthy Transitions checklist (see "script pad") can be used to track accomplishments. Each module provides strategies that families and professionals can use to help youths to develop a particular skill. The curriculum emphasizes self-determination and the active involvement of young adults who have developmental disabilities in their own health care.

The modules begin with a vignette that illustrates a transition "success story". This is followed by didactic information and a list of references and resources for skill development. A table with "tips for collaboration" lists concrete steps that youths, families, service coordinators, and health care providers can take in order to facilitate the transition process. A self-assessment quiz is included at the end of each module.

In addition to the Continuing Education Modules, the Healthy Transitions project offers Lessons Plans, Videos and a Moderator Guide for educators that can be used in group settings with young adults. Our website also features a secure network of personal health sites called **MY PLACE** that link youths to a personal transition team for care coordination, planning, and setting priorities during the transition to adulthood.

Please visit us at HealthyTransitionsNY.org to find out more. We welcome feedback!

Bill

Bill is a 24 year old man with spina bifida who has a learning disability and some difficulties with short term memory. His circle of support includes his sister, who often helps him to get to medical appointments.

Starting several years ago, Bill has practiced scheduling his own medical appointments. Initially he did this with his parents’

supervision. Over time he has become used to the routine. He is now very comfortable with this responsibility.

Bill has made it a habit to set aside his date book and a pen when he calls to schedule an appointment, so that he is prepared to write down information. It has also become routine to repeat back the date and time of appointments, so that he knows it is accurate. His sister helps to schedule transportation.



Scheduling an Appointment

Learning Objectives:

- 1. Name three roadblocks that are commonly encountered by youth who have developmental disabilities when scheduling a medical appointment.**
- 2. List preferences of youth with developmental disabilities, and their families, for the scheduling of medical appointments.**
- 3. Name strategies for minimizing anxiety during medical visits, invasive procedures, and hospital stays.**
- 4. Know where to locate current information about accessible design of healthcare facilities as defined by the Americans with Disabilities Act.**
- 5. List agencies and institutions that provide transportation training for adolescents and young adults who have developmental disabilities.**



Scheduling an Appointment

Calling a doctor's office to schedule a medical appointment is a skill that can be acquired by most adolescents and young adults who have a developmental disability. This is accomplished over time with practice, support, and collaboration. Parents and medical office staff can promote development of this skill by encouraging the adolescent or young adult to sign-in at medical visits and to schedule their own appointments. This is a concrete and practical way to build social skills and to foster self-determination. A positive interaction at the sign-in desk "sets the stage" for effective communication, respect, and trust during the subsequent health care encounter. One cannot underestimate the impact this has on the overall quality of care that is delivered at a medical visit.

It's important for families, service coordinators, and medical office staff to understand and anticipate roadblocks that are commonly encountered by youth who have developmental disabilities at medical visits so that accommodations can be made. These roadblocks are:

- **Anxiety about health care encounters**
- **Inaccessible design of medical offices**
- **Transportation barriers**

Strategies for recognizing these barriers and information about how to make accommodations are outlined below.

Accommodations for Anxiety

In 2007 the New York State Developmental Disabilities Planning Council conducted a statewide survey of families in order to identify their preferences for the scheduling of medical and dental appointments for adolescents and young adults who have developmental disabilities. This information was organized into strategies that health care providers and families can use to make health care visits easier. The #1 recommendation was "that doctors, dentists, and staff have an understanding of the anxiety that individuals may have about medical and dental visits."

Families suggested the following strategies for anticipating and minimizing anxiety when scheduling health care visits for adolescents and young adults who have developmental disabilities:

- **Schedule appointment at a time that is best for the individual, such as the first or last appointment of the day.**
- **Allow extra time for the appointment**
- **Have short wait times in a low stress, quiet environment, or separate waiting area**
- **Ask adolescents and young adults whether they would like family members or a member of their Circle of Support to participate in the visit**

As adolescents and young adults who have developmental disabilities take on responsibility for scheduling of their own medical and dental appointments, it is important to openly acknowledge their anxiety about health care encounters. Asking adolescents and young adults to identify and discuss their preferences for the scheduling of medical appointments will empower them to request appointment times that work best for them.

Strategies for minimizing anxiety should be routinely and explicitly discussed prior to blood draws or other invasive procedures, or when a hospitalization is scheduled. This is best accomplished during a dedicated visit to answer questions, address concerns, and identify specific strategies for the individual. Often adolescents and young adults and/or their families have ideas or suggestions that are easy to implement or accommodate. It may also be helpful to sit down together to review a generic list of strategies for minimizing anxiety, in order to identify an individualized plan. See table on page 5. Family caregivers, the youth's Circle of Support, and service coordinators can also help to identify the supports and/or accommodations that a young adult with a developmental disability will need in order to minimize anxiety during a health care encounter. These accommodations should be explicitly recognized by office staff and documented in the medical chart.

Strategies for Minimizing Anxiety About Health Care Encounters

Desensitization

Sometimes a “dry run” to visit a new medical office or to sit in a dental chair is all that is needed to allay anxiety. Many hospitals offer pre-op tours upon request, or have virtual tours on their website that offer a “sneak peek” of the physical environment. This can help to identify situations or settings that are anxiety provoking so that accommodations can be made. Some hospitals have developed materials and services specifically for patients with autism and/or other developmental disabilities. Contacting a child-life specialist at a health care facility for assistance before a scheduled hospitalization or invasive procedure is often very helpful.

Address Sensory Issues

The noise or lighting in a hospital or medical office may not be well tolerated by adolescents and young adults who have sensory processing differences. Anticipating this and using headphones, sunglasses or other strategies from an individualized sensory diet can make it easier to tolerate a medical visit, hospital stay, or an invasive procedure.

Explain What Will Happen in a Familiar Communication Style

For adolescents and young adults who are non-verbal or primarily visual learners, storyboards that outline what will happen during a hospital stay or procedure can be very helpful as well. These storyboards can be reviewed at home prior to the procedure, in a familiar setting, as well as during the procedure itself. This process allows adolescents and young adults to place the procedure in context and thereby retain a sense of control. Visual schedules, First/Then demonstrations and other strategies that families can use are illustrated in the videos for this unit on our website: http://healthytransitionsny.org/skills_media/video_show.

Office staff who are familiar with these simple and effective strategies improve the quality of health care that is delivered to patients who have developmental disabilities.

Role Play

Rehearsing what will happen during a hospital stay or invasive procedure can ameliorate stress as well. It may help to use “props” such as exam gloves or hospital masks. This fosters understanding and familiarity, which will give the adolescent or young adult a sense of control during the procedure itself.

Comfort and Distraction Items

Although comfort items such as stuffed animals may be considered inappropriate in school or other settings, it is okay to use these during an invasive procedure or hospital stay. Distraction with a favorite DVD, music, or other activity is another effective strategy.

Pre-medication

Last but not least, medications for managing anxiety and pain should be discussed. Options include pre-medication at home with a long lasting sedative, the application of a topical numbing cream prior to venipuncture, and /or conscious sedation at the time of the medical or dental procedure under the supervision of a trained health care provider. Some adolescents and young adults may have atypical responses to medications that are routinely used for sedation or anxiety. For example, an individual with autism may become dis-inhibited and irritable when Versed is used for a procedure.

Health care providers should specifically ask whether there is a history of adverse responses to standard medications before prescribing any sedative. In this case it is often possible to give an alternative medication that is known to be effective for the individual, or an extra dose of a medication that is routinely taken to manage challenging behaviors.

Accommodations for Mobility, Sensory, and Communication Impairments

Mobility, sensory, and/or communication impairments are common among youth who have developmental disabilities. Sometimes staff may not recognize or know how to assist patients with these disabilities. It often falls to the patient to explain his/her needs (and rights) for accessible health care. The scheduling of an appointment thus is a skill that requires adolescents and young adults to be comfortable with self-advocacy. This comes with practice, and with an understanding of one's legal rights. Local, state and federal laws regulate standards for physical access to health care facilities. Key legislation includes Section 504 of the Rehabilitation Act of 1973, which requires programs or services that receive federal assistance to meet federal accessibility standards. The Americans with Disabilities Act (ADA) and the Architectural Barriers Act (ABA) are federal laws that set minimum standards for accessible design of health care facilities, such as low counter and service windows for people who cannot stand and wheelchair accessible toilets.

Because the ADA and ABA apply only to new buildings and renovations of existing health care facilities, many existing medical and dental offices do not meet these minimum requirements. It is therefore important for adolescents and young adults to specifically ask whether a health care facility is fully accessible when scheduling an appointment. A medical office that is "disability-friendly" routinely asks new patients whether accommodations are needed. The table below lists examples of accommodations for mobility, sensory and communication impairments. Universal design refers to the creation of effective design solutions for all people, rather than specific accommodations for people with disabilities. As our society ages, health care providers increasingly recognize the practical as well as philosophical advantages to this approach.

Accommodations at Medical Offices for Persons with Disabilities

Mobility impairment

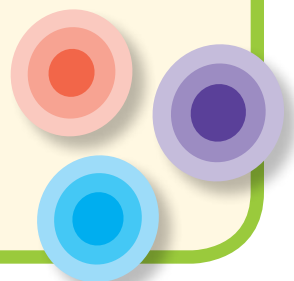
- Accessible parking spaces close to entrance
- Power door operators at interior and exterior entrances
- Ramps, curb cuts, and elevator access
- Low counters and service windows to accommodate individuals who cannot stand while registering for an appointment
- Wheelchair accessible toilet
- Scales that allow for people to be weighed while sitting in a wheelchair
- Motorized, adjustable-height treatment and examining chairs and tables

Sensory impairment

- Text telephones
- Qualified sign language interpreters
- Audio and visual alarm systems
- Large print documents for people with low vision
- Raised lettering and Braille to identify rooms and elevator controls

Communication impairment

- Telephone line or qualified interpreter for foreign language translation
- Aide who can assist with use of communication device
- Family or friend serves as scribe at medical visits to writes down treatment plan
- Designated members of "Circle of Support" listed on HIPAA form



Communication

Although health care guardianship and the general topic of health information sharing are addressed in detail in other sections of this curriculum, it is important for adolescents and young adults to have a general understanding of paperwork that is required at the registration desk, so that they come well prepared to medical and dental appointments. They should anticipate that they will be asked to provide (a) insurance information, and to sign (b) Consent to Treat and (c) HIPAA privacy forms, which are updated annually. HIPAA stands for the Health Insurance Portability and Accountability Act of 1996, which establishes security and privacy standards for the use and disclosure of “protected health information.” The HIPAA consent forms are signed by the parent or guardian until age 18. Beyond that time, unless guardianship is established, the youth must sign a HIPAA consent form in order to permit the health care provider to share personal health information with family members, his/her Circle of Support, or any other individuals specified by the youth. In other words, parents of adolescents and young adults who have developmental disabilities do not automatically retain access to health information of their adult child. Physicians cannot legally discuss medical care of adult children with the parent unless a signed HIPAA consent form is placed in the patient chart. It is very important to be aware of this, particularly if adolescents and young adults are in the process of developing skills for independently navigating the health care system, or if they will require some level of ongoing support. An important aspect of skill development for the scheduling of an appointment is acknowledging whether health information sharing is warranted, and taking responsibility for documenting this legally on the HIPAA form or with guardianship papers. If this is not addressed pro-actively, HIPAA becomes a communication barrier between health care providers, the patient, and family members or the “Circle of Support” for a young adult who has a developmental disability. Office staff can help families by reminding patients about this issue.

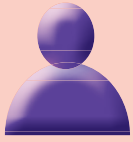
Transportation

A key component of skill development for the scheduling of an appointment is being able to plan and coordinate transportation. Many adolescents and young adults who have developmental disabilities rely on friends or family, or use para-transit or other forms of public transportation. Medicaid-funded transportation is available to adolescents and young adults who are publicly insured. Most high schools offer transportation training in Life Skill classes or as part of a student’s Individualized Education Plan. Centers for Independent Living, Vocational Rehabilitation Services (VESID), and regional Developmental Disabilities Services Offices for the Office for Persons with Developmental Disabilities (DDSO-OPWDD) may also offer transportation training. Adolescents and young adults who have vision impairment/blindness are eligible to receive specialized travel training called orientation and mobility (O&M) instruction as part of their special education program or via the Commission for the Blind and Visually Handicapped (CBVH). Organizations that train seeing, hearing, and companion dogs also instruct individuals who apply for their services on how to use public transportation safely with the assistance of their service animal. Travel training for adolescents and young adults who have intellectual disabilities focuses on safety and an individual’s awareness of personal space and the environment. Travel training for adolescents and young adults who have physical disabilities focuses on specific motor skills such as how to use a wheelchair lift. Individuals are also taught how to appropriately ask for assistance, how to access public and para-transit, and how to assert their rights when traveling and in other social situations. Transportation training is beyond the scope of this curriculum. However it is relevant to skill development for scheduling an appointment in that adolescents and young adults should be aware that the scheduling of an appointment is incomplete until arrangements have also been made for transportation to that appointment.

In Summary

Being able to schedule an appointment is a skill that can be acquired by most adolescents and young adults who have developmental disabilities. Families, service coordinators, and health care providers can help by addressing three common roadblocks: (1) anxiety about health care encounters, (2) inaccessible design of medical offices, and (3) transportation barriers. Explicit recognition of these barriers helps all involved to develop person-centered solutions. This sets the stage for an effective health care visit.

Scheduling an Appointment Tips for Collaboration



**Adolescent/
Young Adult**

Discuss anxiety about medical and dental visits with family, friends, health care providers and service coordinators. Decide on strategies that will minimize anxiety.

Identify accommodations that you will need during a medical visit and ask whether these are in place when scheduling an appointment.

Practice signing in for appointments by presenting insurance card to office staff.



Family

Involve adolescent or young adult in scheduling of medical and dental visits at an early age by having him/her observe your phone calls initially. Gradually ask him/her to take on more responsibility.

Give adolescent or young adult his/her own calendar or agenda for organizing information about health care appointments.

Give adolescent or young adult a copy of his/her insurance card to present at the sign-in desk.

Make sure that transportation training programs offered at school or via VESID programs include instruction in the use of Medicaid funded transportation for health care visits.



**Health Care
Providers**

Flag patient charts so that appointments are routinely scheduled at a time that is best for the individual, such as the first or last appointment of the day.

Block appointments as extended visits so that the encounter isn't rushed. Consider time based billing for visits that require prolonged counseling and discussion with family members.

Complete registration in the exam room if the waiting area is crowded.

Routinely and openly discuss strategies for minimizing anxiety prior to invasive procedures or hospital stays. Discuss pre-medication options.



**Service
Coordinators**

Ask adolescent or young adult to discuss upcoming medical and dental appointments, e.g. why they were scheduled.

Discuss accommodations that are needed for health care visits, and how the youth can advocate for this.

Discuss anxiety about medical and dental visits with youth, family, and health care providers. Help implement strategies that will minimize anxiety.

Review and document on the HIPAA consent form members of the youth's Circle of Support with whom communication regarding medical care is permitted.

Resources

The Center for Universal Design at North Carolina State College of Design

<http://www.design.ncsu.edu/cud/>

Child Life Council

Evidence based practice statement preparing children & adolescents for medical procedures.

Koller, D. (2007)

<http://www.childlife.org/>

National Center for Cultural Competence

<http://www11.georgetown.edu/research/gucchd/nccc/>

New York State Commission for the Blind and Visually Handicapped (CBVH)

<http://www.ocfs.state.ny.us/main/cbvh/>

New York State Medicaid Transportation List

http://www.emedny.org/ProviderManuals/Transportation/PDFS/Archive/Transportation_PA_Guidelines_Contact_List_2009-4.pdf

SNAP, Special Needs Advocacy Partners

Supporting Patients with Autism and other Developmental Disabilities in Healthcare: A manual of strategies to improve the experience of care.

Klayman, Gail J., M.Ed. CCLS, (2009)

<http://www.cincinnatichildrens.org/svc/find-professional/k/gail-klayman.htm>

Travel Training for Youth with Disabilities

NICHCY Transition Summary, Volume 9, June 1996

<http://www.nichcy.org/InformationResources/Documents/NICHCY%20PUBS/ts9.pdf>

U.S. Department of Justice

Access to Medical Care for Patients with Mobility Impairments (2010)

http://www.ada.gov/medcare_mobility_ta/medcare_ta.htm

Available by calling 800-514-0301 (voice), 800-514-0383 (TTY).

United States Department of Justice ADA Homepage

Information and technical assistance on the Americans with Disabilities Act

<http://www.ada.gov/>

Vocational and Educational Services for Individuals with Developmental Disabilities (VESID)

Driver evaluation and training services.

http://www.vesid.nysed.gov/current_provider_information/vocational_rehabilitation/policies_procedures/0440_driver_evaluation_and_training/procedure.htm

Quiz

- 1. The three major barriers encountered by youth who have developmental disabilities when scheduling a medical appointment are:**
 - a. Anxiety about health care encounters; Inaccessible design of medical offices; Difficulties with scheduling transportation
 - b. Lack of insurance; Co-payment costs; HIPAA violation
 - c. Pediatricians will not accept adult patients; Youths are not used to making phone calls; Parents are "afraid to let go"
 - d. Service coordinator is not available to schedule appointments; Attitude that a doctor's visit is scheduled only when sick; Health records are not available

- 2. According to families, the single most significant issue for health care professionals to be aware of when scheduling medical or dental appointments for youth who have developmental disabilities is:**
 - a. Physical access
 - b. Health information access
 - c. Insurance
 - d. Anxiety
 - e. Transportation

- 3. Strategies for reducing anxiety during medical/dental visits include:**
 - a. Minimizing time in the waiting room
 - b. Pre-medication with a mild sedative
 - c. Story boards or picture schedules
 - d. Distraction
 - e. All of the above

- 4. Standards for accessible health care facilities under ADA and ABA include:**
 - a. Power door operators at interior and exterior entrances
 - b. Scales that allow for people to be weighed while sitting in a wheelchair
 - c. Motorized, adjustable-height treatment and examining chairs and tables
 - d. Text telephones and qualified sign language interpreters
 - e. All of the above

- 5. Agencies and institutions that provide transportation training for adolescents and young adults who have developmental disabilities include:**
 - a. Vocational and Educational Services for Individuals with Developmental Disabilities (VESID)
 - b. Office for Persons with Developmental Disabilities (OPWDD)
 - c. Life skills programs for special education students
 - d. Commission for the Blind and Visually Handicapped (CBVH)
 - e. All of the above

Answer key: 1(a); 2(d); 3(e); 4(e); 5(e)

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