

Speaking Up at the Doctor's Office

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 speak up at the doctor's office.

Speaking Up at the Doctor's Office

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

- ✓ Prepare for a doctor's appointment by writing down questions, role-play, or rehearsal.
- ✓ Introduce him/herself to his/her doctor or nurse.
- ✓ Explain the role of his/her aide or family member during a medical visit.
- ✓ Ask questions during health care encounters.
- ✓ Speak up if he/she does not understand or if he/she would like more information.

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!

Nikki

Nikki is a 24-year-old woman with cerebral palsy who gets out and about with the assistance of a personal care attendant named Sue. Nikki recently established medical care with a new doctor in the adult health care system. At the initial visit she was dismayed that this physician made recommendations and discussed a medical treatment plan with Sue, rather than speaking directly to Nikki.



Because Nikki has spasticity and dysarthria, it can be difficult to understand her speech, particularly when she is emotional. It upset Nikki that the physician made assumptions about her ability to participate in her own medical care. Nikki's dysarthria worsened as she became emotional. Her spasticity increased as well, exacerbating the situation.

Nikki addressed the situation at a follow-up appointment. She greeted the physician when he entered the exam room. She introduced Sue and explained Sue's role as her personal care attendant. Nikki's dysarthria was much improved because she had rehearsed what she would say. Nikki's physician apologized, acknowledging that he had assumed that Nikki was cognitively disabled based on her difficulty speaking. He made a notation in Nikki's chart about her dysarthria. He made sure his office staff understood that questions and instructions should be addressed directly to Nikki. He also asked his office staff to schedule future appointments with extended time to allow for effective doctor-patient communication.

Speaking Up at the Doctor's Office **Learning Objectives:**

- 1. Define linguistic competence.**
- 2. List three basic tenets of effective communication with youth who have developmental disabilities.**
- 3. Provide an example of person-first language.**
- 4. Give three examples of auxiliary aids & translation services that are mandated by the Americans with Disabilities Act.**
- 5. Name the five P's of effective self-advocacy.**



Speaking Up at the Doctor's Office

Good communication is good medicine. This module outlines strategies for effective communication with adolescents and young adults who have developmental disabilities.

Linguistic competence

Assumptions are sometimes made about the ability of young adult patients who have developmental disabilities to engage in, much less lead a discussion during a health care encounter. This is partly due to generic “teen” issues related to autonomy and family dynamics. More often than not, though, health care providers lack training in cultural and linguistic competence vis-à-vis the developmental disabilities.

The National Center for Cultural Competence defines linguistic competence as:

The capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who have low literacy skills or are not literate, individuals with disabilities, and those who are deaf or hard of hearing. Linguistic competency requires organizational and provider capacity to respond effectively to the health and mental health literacy needs of populations served. The organization must have policy, structures, practices, procedures, and dedicated resources to support this capacity. Guiding values and principles for language access include:

- *Services and supports are delivered in the preferred language and/or mode of delivery of the population served.*
- *Written materials are translated, adapted, and/or provided in alternative formats based on the needs and preferences of the populations served.*
- *Interpretation and translation services comply with all relevant Federal, state, and local mandates governing language access.*
- *Consumers are engaged in evaluation of language access and other communication services to ensure quality and satisfaction.*

Goode & Jones (modified 2009). National Center for Cultural Competence, Georgetown University Center for Child & Human Development <http://nccc.georgetown.edu/foundations/frameworks.html#lcdefinition>

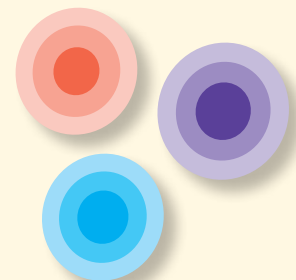
General strategies for improving linguistic competence at medical practice sites are listed on the facing page. This module will provide simple and concrete recommendations that can be readily implemented by health care teams in order to improve their linguistic competence when serving patients who have developmental disabilities.



Strategies for Improving Linguistic Competence at Medical Offices

- Foreign language interpretation services including distance technologies
- Sign language interpretation services
- Translation services including those of:
 - Legally binding documents (e.g., consent forms, confidentiality and patient rights statements, release of information, applications)
 - Signage
 - Health education materials
 - Public awareness materials and campaigns
- Multilingual telecommunication systems
- Videoconferencing and tele-health technologies
- TTY and other assistive technology devices
- Computer assisted real time translation (CART) or viable real time transcriptions (VRT)
- Print materials in easy to read, low literacy, picture and symbol formats
- Materials in alternative formats (e.g., audiotape, Braille, enlarged print)
- Varied approaches to share information with individuals who experience cognitive disabilities
- Materials developed and tested for specific cultural, ethnic and linguistic groups
- Bilingual/bicultural or multilingual/multicultural staff
- Cultural brokers (someone who is comfortable linking or mediating between groups or persons of differing cultural backgrounds)

Adapted from National Center for Cultural Competence, Georgetown University Center for Child & Human Development <http://nccc.georgetown.edu/foundations/frameworks.html#lcdefinition>



Basic tenets of effective communication

Health care professionals can encourage adolescents and young adults who have developmental disabilities to speak up during health care encounters by following these three basic tenets of effective communication:

1. **Treat the person, not the diagnosis**
2. **Presume competence**
3. **Foster self-determination**

Treat the person, not the diagnosis

Kathie Snow, a mother and advocate, writes about doctor-patient-family communication in her book *Disability Is Natural* (<http://www.disabilityisnatural.com/>):

Words are powerful. Old, inaccurate descriptors and the inappropriate use of medical diagnoses perpetuate negative stereotypes and reinforce an incredibly powerful attitudinal barrier—the greatest obstacle facing individuals with disabilities.

Kathie Snow advocates for the use of People-First language, “because it puts the person before the disability.” Examples of person-first alternatives to words and phrases that reflect (and shape!) negative perceptions of people who have developmental disabilities are provided in the chart below.

Person-first language reflects the paradigm shift that is summarized by the Kathie Snow’s phrase that “Disability Is Natural”. Person-first language is a mindset, and not just a list of politically correct terms. For example, saying “Nikki is a teen with cerebral palsy who uses a wheelchair” is preferred over saying “Nikki is a wheelchair-bound cerebral palsy patient.” Person-first language avoids the bias that Nikki is defined by

USE PERSON-FIRST LANGUAGE:	IN PLACE OF:	BECAUSE:
Person without a disability	Normal	Use of normal categorizes others as abnormal. Acknowledging the range of abilities among people is more inclusive.
Person with a disability	Disabled	This is the basis of person-first terminology
Person with cognitive, intellectual, or developmental disability	Mentally retarded	Recommended by 2002 AAMR position statement to describe persons with intellectual disabilities.
Person who is visually impaired or blind	Blind person	Person-first terminology
Deaf person, or person who is hard of hearing	The deaf, deaf and dumb, deaf-mute	Deaf is often capitalized to reflect membership in a culture involving a unique language.
Person who has cerebral palsy	Palsied, spastic	Recommended by UCP National in 2003
Person who has autism	Autistic person	Person-first terminology

Adapted from Lieberman, L. J., & Arndt, K. (2004). *Language to live and learn by*. *Teaching Elementary Physical Education*, 15(2), 33-34

her disability, and the assumption that her wheelchair is confining. In fact, the wheelchair is the key to Nikki's mobility and independence!

It's important to be aware that person-first language is criticized in academic circles and among advocates who view developmental disability not as a medical diagnosis but in terms of neuro-diversity. Critics have pointed out that person-first language implies that a developmental disability is a disease, and not an integral part of person-hood. Jim Sinclair, who has written an essay about autism rights called "Don't Mourn For Us" (http://www.autreat.com/dont_mourn.html) prefers to be called autistic: "If I did not have an autistic brain the person I am would not exist. I am autistic because autism is an essential feature of me as a person." Similarly, many prefer "Deaf" over the phrase "person who is hearing impaired". Deaf is capitalized because it reflects membership in a culture involving a unique language and communication. "Deaf person" is accepted in the sense that "Italian person" or "French person" is also accepted. Although proponents of the neuro-diversity viewpoint might disagree with the rationale for person-first language, most would agree with Kathie Snow's declaration that "Disability Is Natural".

Perhaps the most practical approach is to simply ask a youth how he/she would like to be addressed! The spirit of "person-first" is what counts. A basic tenet of effective communication with youths who have developmental disabilities is to recognize that medical labels don't define the patient. This is generally true when caring for any patient, regardless of the diagnosis. Additional communication tips that may be helpful to professionals who are unfamiliar or unsure about how to interact with young adult patients who have developmental disabilities are listed on page 8.

Presume Competence

People perform best when they feel valued and supported. It is particularly important to remember this when communicating with youths who have developmental disabilities. For example, youths with intellectual disabilities may take a bit longer to formulate a response to a question, or, generally, to express themselves. However, they still have something to say! Some youths with cortical vision impairment require a full 20-30 seconds to process and respond to what they see. And many youths with autism are better able to communicate with assistive technology such as a communication board or a voice output device. Professionals who are unfamiliar with these communication styles may inadvertently cut off someone mid-thought, or assume that communication is not possible. This dynamic can be subtle or overt. In either event, the result is that the person does not feel valued. This further confounds the situation because the patient is not supported to communicate to his/her full potential. On the other hand, when professionals presume competence, they maintain the hope and the expectation of mutual understanding. This attitude leads family, friends, and professionals to always create more opportunities for communication. Medical professionals may not be familiar with the array of communication styles and assistive technologies available to youths with developmental disabilities. This is not required and should not be expected as long as ADA-compliant auxiliary aids and translation services are available (see table below). However it is essential that health care professionals presume competence. Communication etiquette that is based on this core value is summarized on page 11.

Auxiliary Aids & Translation Services Mandated by Americans with Disabilities Act

- Text telephones
- Audio and visual alarm systems
- Qualified sign language interpreters
- Large print documents for people with low vision
- Raised lettering and Braille to identify rooms and elevator controls
- Telephone line or qualified interpreter for foreign language translation
- Auxiliary aides who can assist with use of communication device
- Scribe or note-taker to write down treatment plan

The Americans with Disabilities Act (ADA) of 1990, Public Law 101-336, 42 U.S.C. §12101, et seq.

Communication Tips

Tips for Communicating with Individuals with Intellectual Disabilities

- If you are in a public area with many distractions, consider moving to a quiet or private location.
- Be prepared to repeat what you say, orally or in writing.
- Offer assistance completing forms or understanding written instructions and provide extra time for decision-making. Wait for the individual to accept the offer of assistance; do not “over-assist” or be patronizing.
- Be patient, flexible and supportive. Take time to understand the individual and make sure the individual understands you.

Tips for Communicating with Individuals Who Are Blind or Visually Impaired

- Speak to the individual when you approach him or her.
- State clearly who you are; speak in a normal tone of voice.
- When conversing in a group, remember to identify yourself and the person to whom you are speaking.
- Never touch or distract a service dog without first asking the owner.
- Tell the individual when you are leaving.
- Do not attempt to lead the individual without first asking; allow the person to hold your arm and control her or his own movements.
- Be descriptive when giving directions; verbally give the person information that is visually obvious to individuals who can see. For example, if you are approaching steps, mention how many steps.
- If you are offering a seat, gently place the individual’s hand on the back or arm of the chair so that the person can locate the seat.

Tips for Communicating with Individuals Who are Deaf or Hard of Hearing

- Gain the person’s attention before starting a conversation (i.e., tap the person gently on the shoulder or arm).
- Look directly at the individual, face the light, speak clearly, in a normal tone of voice, and keep your hands away from your face. Use short, simple sentences. Avoid smoking or chewing gum.
- If the individual uses a sign language interpreter, speak directly to the person, not the interpreter.
- If you telephone an individual who is hard of hearing, let the phone ring longer than usual. Speak clearly and be prepared to repeat the reason for the call and who you are.
- If you do not have a Text Telephone (TTY), dial 711 to reach the national telecommunications relay service, which facilitates the call between you and an individual who uses a TTY.

Tips for Communicating with Individuals with Mobility Impairments

- If possible, put yourself at the wheelchair user’s eye level.
- Do not lean on a wheelchair or any other assistive device.
- Never patronize people who use wheelchairs by patting them on the head or shoulder.
- Do not assume the individual wants to be pushed — ask first.
- Offer assistance if the individual appears to be having difficulty opening a door.
- If you telephone the individual, allow the phone to ring longer than usual to allow extra time for the person to reach the telephone.

Tips for Communicating with Individuals with Speech Impairments

- If you do not understand something the individual says, do not pretend that you do. Ask the individual to repeat what he or she said and then repeat it back.
- Be patient. Take as much time as necessary.
- Try to ask questions, which require only short answers or a nod of the head.
- Concentrate on what the individual is saying.
- Do not speak for the individual or attempt to finish her or his sentences.
- If you are having difficulty understanding the individual, consider writing as an alternative means of communicating, but first ask the individual if this is acceptable.

Source: Office of Disability Employment Policy at <http://www.dol.gov/odep/pubs/fact/comucate.htm>

Self-Determination

Self-determination is a theory about motivation that was developed in the 1980s by social science researchers Edward L. Deci and Richard M. Ryan. It has been applied to a wide variety of settings. In particular, self-determination theory has revolutionized the field of special education. Self-determination is defined as a combination of attitudes and abilities that leads people to set goals for themselves and to take the initiative to reach those goals. Dozens of curricula have been developed to enhance self-determination for students with disabilities. When compared with conventional special education curricula, students graduating from self-determination programs are more successful in making the transition to adulthood as measured in terms of employment and independent living. Self-determination also holds great potential for improving health outcomes for youths with developmental disabilities.

In the context of health care, self-determination is the opposite of “learned helplessness.” Learned helplessness is a phenomenon that has been well described in the medical literature. It is best encapsulated by the common scenario of a doctor or nurse who directs all conversation to the parent, rather than to the young adult patient. This is a cue to the adolescent that it is ok to be passive. Over time the adolescent “learns” to be “helpless” during health care encounters. This is often unintentional, and may be due to many factors.

“Letting go” in order to give adolescents who have developmental disabilities autonomy during a health care visit is a delicate topic for both families and health care providers. There is a very natural tendency for all involved to be protective. The reality is that most families have had to develop strong advocacy skills over the years, to assure that high quality medical care is provided. Yet it is critical during adolescence that parents and health care providers give youths the opportunity to demonstrate, both to themselves and to others, that they are capable of active involvement in their own health care. Self-determination can only be learned from real world experience (including mistakes) and an open, supportive acknowledgement of disability. This way, youths enter the adult health care system with the skills that are needed to navigate services and to engage in meaningful discussions. When viewed in this light, the transition to adulthood isn’t so much about “letting go” as it is about “creating opportunities” for youths to develop skills and for parents to be pro-active and future oriented. Health care encounters that emphasize self-determination (as opposed to learned helplessness) focus explicitly on engaging the youth in his/her own health care. The communication skills that are developed in this context are collectively known as Self Advocacy.

Self-Advocacy

Self-advocacy refers to an individual’s ability to effectively communicate, convey, negotiate or assert his or her own interests, desires, needs, and rights. It involves making informed decisions and taking responsibility for those decisions (VanReusen et al., 1994). Several examples of self-advocacy are provided below:

- **When scheduling an appointment, a Deaf youth requests sign language interpretation services.**
- **A young woman with cerebral palsy asks her pharmacist how to open a childproof prescription bottle.**
- **A young man with Down syndrome tells his doctor that he does not like the side effects of a medication.**
- **A man with cerebral palsy uses his communication device to alert a caregiver that the baclofen pump he had implanted for managing his spasticity is not delivering his medications correctly.**

Since individuals know their own situations the best, it is absolutely essential that their voice be heard during all health care encounters. This is a matter of patient safety and should be standard of care.

A grass-roots organization called Self Advocacy Association of New York State (<http://www.sanys.org/>) can help youths to develop self-advocacy skills by offering opportunities for role-play and practice in a supportive, small group setting. Youths learn how to describe a problem, and also how to listen to the response. The video entitled “Role of Aides at a Medical Appointment” on the HealthyTransitionsNY.org website at http://healthytransitionsny.org/skills_media/video_show illustrates how Nikki, who is featured in the vignette at the beginning of this module, learned how to speak up for herself with the help of the Self Advocacy Association of New York State.

The Five P's of Self-Advocacy

Patients are often more successful at self-advocacy if the particular problem they are describing can be connected to protections covered by the “**Patient Bill of Rights**” or if **Patient Safety** is invoked. It is also helpful to remember the other “P’s” of self advocacy:

Prepared: Self-advocates who are prepared are able to articulate what their concern is, why it should be addressed, and what should be done. Sometimes the issue relates to interpersonal dynamics. At other times, it may be a medico-legal matter. Regardless, a self-advocate is most effective if he/she is prepared to speak up.

Positive: One of the secrets of Self-advocacy is to be positive. Expect the best, assume that others also have good intentions, and stay positive!

Persistent: It is important, though, to combine persistence with that positive outlook. Being positive alone is often not effective. Being persistent, without being polite or positive can backfire. However, being both persistent and positive gets results!

The Five “P’s” of Self Advocacy

1. Patient Bill of Rights
2. Patient Safety
3. Prepared
4. Positive
5. Persistent

Legal expertise is not a pre-requisite for self-advocacy. Effective self-advocates are neither adversarial nor contentious. Rather, they are secure in the conviction that their viewpoint should be considered, and are comfortable with speaking up. Youths who have self-advocacy skills are therefore better able to navigate the adult health care system. They are also better able to partner with their health care providers. This improves adherence to medical recommendations, patient safety, and ultimately quality of care, satisfaction with care, and health outcomes.

In Summary

Health care professionals can encourage adolescents and young adults who have developmental disabilities to speak up during health care encounters by following these three basic tenets of effective communication:

- Treat the person, not the diagnosis
- Presume competence
- Foster self-determination

Youths who have self advocacy skills are better able to speak up at the doctor’s office. Since youths know their own situation best, it is absolutely essential that their voice be heard during all health care encounters.

Communication Etiquette

- **Presume competence!**
- **Establish eye contact and shake hands at the beginning of every visit.**
- **Acknowledge the youth's "Circle of Support"**

If caregivers accompany the youth to the appointment, ask the youth to make introductions and to clarify the role of caregivers. Ask youth if caregivers should step out or stay for the visit.
- **Help to set the youth at ease.**

Caregivers often know how to do this. Humor is a great ice-breaker.
- **Ask about the youth's preferred communication style.**

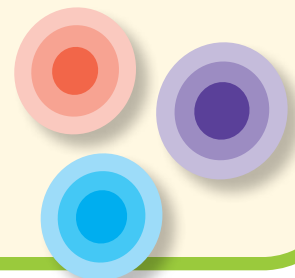
Be sure to document this in the medical record.
- **Do not hurry the visit.**

Allow plenty of time for youths to ask questions and/or discuss concerns in his/her own words. Flag the chart so that appointments are routinely scheduled as extended visits. Use time-based billing codes so that effective communication can occur and high quality care can be provided.
- **Ask youth to describe concerns in his/her own words.**

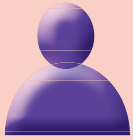
Suggest that youths rehearse or write down questions prior to the medical visit.
- **Talk directly and clearly.**

Avoid medical jargon when making recommendations.
- **Ask youths to repeat back information in own words.**

This keeps a youth actively involved in the visit. It is also a good way to assess comprehension and memory.
- **Write down key information and recommendations**
- **Establish eye contact and shake hands at the end of every visit.**



Speaking Up at the Doctor's Office Tips for Collaboration



Adolescent/
Young Adult

Write down questions before going to a medical appointment.
Practice introducing yourself.
If you don't understand something, or if you would like more information, speak up!
Join a self-advocacy group.



Family

Give son or daughter the opportunity to practice self-advocacy skills in real-world situations.
Allow youth to make (and learn from!) his/her mistakes.
Step back at medical visits. Encourage your son or daughter to do the talking.
View the videos for "Speaking up at the Doctor's Office" with your son or daughter: http://healthytransitionsny.org/skills_media/video_show
Help your son or daughter to understand the five P's of self-advocacy: Prepared, Polite, Persistent, Patient Bill of Rights, Patient Safety.



Health Care
Providers

Presume competence.
Establish eye contact and shake hands with patients who have developmental disabilities
Use person-first language.
Gives youths the time that they need in order to speak up.
Conduct periodic assessments of linguistic competence with the health care team at your practice site.



Service
Coordinators

Encourage youths to write down questions before medical appointments.
Provide youths with information about self-advocacy programs in the community.
Help youths to understand the five P's of self-advocacy: Prepared, Polite, Persistent, Patient Bill of Rights, Patient Safety

Resources

Americans with Disabilities Act

ADA Technical Assistance Centers

<http://www.adata.org/Static/Home.aspx>

Pacer Center ADA Q&A Health Care Providers

<http://www.pacer.org/publications/adaqa/health.asp>

Self-Evaluation Checklist for Health Care Facilities and Service Providers to Ensure Access to Services and Facilities by Patients Who Are Blind, Deaf-Blind, or Visually Impaired, Scott Marshall and Elga Joffee, American Foundation for the Blind

<http://www.afb.org/Section.asp?SectionID=3&TopicID=32&DocumentID=529>

Linguistic Competence

American Speech Language Association

www.asha.org/publications/journals/submissions/person_first.htm

Disability.gov

www.disability.gov/community_life/disability_etiquette

National Center for Cultural Competence

<http://nccc.georgetown.edu/>

Autism

Paula Kluth: Toward More Inclusive Classrooms and Communities

<http://www.paulakluth.com/>

The Gray Center of Social Learning and Understanding

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

Non-Verbal Communication

Communication matrix for parents and professionals

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

Teaching Pre-Linguistic communication

<http://nationaldb.org/NCDBProducts.php?prodID=118>

Deaf, Blind, Deaf-Blindness

National Association for the Deaf

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

National Federation of the Blind

<http://www.nfb.org/nfb/Default.asp>

National Consortium on Deaf-Blindness

<http://nationaldb.org/>

Deaf Wellness Center, University of Rochester, Rochester, New York

<http://www.urmc.rochester.edu/dwc/>

National Technical Institute for the Deaf, Rochester Institute of Technology

<http://www.ntid.rit.edu/>

Assistive Technology

AbleData

<http://www.abledata.com/abledata.cfm?pageid=19327&top=10825&deep=2&trail=22&ksectionid=19327>

RJCooper and Associates

Software and Hardware for People with Disabilities

<http://www.rjcooper.com/>

Self Advocacy

Self Advocacy Association of New York State

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

Quiz

1. Linguistic competence is:

- a. A checklist for rating the legibility of handwritten documents
- b. Health information access
- c. The ability to communicate effectively, and convey information in a manner that is easily understood by diverse audiences
- d. Relevant to Deaf population only
- e. Equivalent to language pragmatics

2. Three basic tenets of effective communication with youth who have developmental disabilities are:

- a. Treat the person, not the diagnosis; Presume competence; Foster self-determination
- b. Accurate diagnosis; Safe treatment; Positive health outcomes
- c. Age-appropriate information; Privacy; HIPAA consent forms
- d. Efficient visits; Written information; Follow-up phone call
- e. Review of history; Physical exam; Counseling

3. An example of person-first language (circle one):

- a. Bill is a young man who has an intellectual disability.
- b. David is normal.
- c. Jane is the handicapped girl who is palsied.
- d. Karen is mentally retarded.
- e. Jake is deaf and dumb.

4. What auxiliary aids and translation service(s) that are mandated by the Americans with Disabilities Act (circle one):

- a. Text telephones
- b. Qualified sign language interpreters
- c. Large print documents for people with low vision
- d. Raised lettering and Braille to identify rooms and elevator controls
- e. All of the above

5. Which is NOT one of the "Five P's" of effective self-advocacy?

- a. Patient Bill of Rights
- b. Patient safety
- c. Polite
- d. Persistent
- e. Prepared
- f. Primary care

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

Notes

A sheet of white paper with horizontal blue lines, typical of a notebook page. The lines are evenly spaced and extend across the width of the page. The word "Notes" is written in purple at the top center.

Notes

A sheet of white paper with horizontal blue lines, typical of a notebook page. The lines are evenly spaced and extend across the width of the page. The word "Notes" is written at the top center in a purple, cursive font.

Acknowledgements

The Healthy Transitions continuing education modules were developed in 2006-2010 with funding support from the New York State Developmental Disabilities Planning Council, the Golisano Children's Hospital at SUNY Upstate Medical University, and the Department of Family Medicine at SUNY Upstate Medical University (Health Resources and Services Administration Grant Award # 2 D54HP05462-04-00). The Healthy Transitions website, curriculum and tools are owned by the New York State Developmental Disabilities Planning Council. All of our materials may be reproduced and distributed for educational purposes.

This module (Speaking Up at Doctor's Office) was written by Katrina Arndt, MEd, PhD, Rebecca Garden PhD, and Nicole Hastings. The Healthy Transitions curriculum was edited by Nienke P. Dosa MD, MPH

Reviewers

Kathy Ahern RN, Community Mental Health Nurse, NY State OPWDD, Central NY DDSO

Sandra M Banas, MST RPA-C, Assistant Professor and Chair, Physician Assistant Studies, College of Health Professions SUNY Upstate Medical University, Syracuse, NY

Heidi Byrd, Student, LeMoyne College, Syracuse, NY

Peter Beatty, PhD, Department of Family Medicine, SUNY Upstate Medical University, Syracuse, NY

Donna M. Cashman, PHN, MS, Manager, Local Health Services, New York State Department of Health

L. Robert Ciota, MS, Consultant Center on Human Policy, Law and Disabilities Studies at Syracuse University, Syracuse, NY

Carl J Crosley, MD, Professor of Neurology and Pediatrics, SUNY Upstate Medical University, Medical Director Enable, Syracuse, NY

John Epling MD, Department of Family Medicine, SUNY Upstate Medical University, Syracuse, NY

Vivian Figueroa, Director of Foundation and Government Relations, St. Mary's Healthcare System for Children, Bayside, NY

Jan Fitzgerald, President, Parent to Parent of NY State

Mary Grace Flaherty, MLS, doctoral student, School of Information Studies, (i-School), Syracuse University, Syracuse, NY

Kimberlee Garver, MSW, Center for Development, Behavior and Genetics, Golisano Children's Hospital, SUNY Upstate Medical University, Syracuse, NY

Tammy Gebo-Seaman, Sibling, Lakeland, FL

Marcia Hagan, Grandparent, Syracuse, NY

Mary Harrington, JD, Parent and Attorney, Fayetteville, NY

Nichole Hastings, Self-Determination Project, NY State OPWDD, Central NY DDSO

Kathy Hutchinson, HOME, Inc., Syracuse, NY

Laurie James MEd, Advocates, Inc., Syracuse, NY

Michele Juda, Upstate Coordinator Parent to Parent of NYS

Irene D. Jurczyk, Associate Director, Mountain Area Health Education Center (MAHEC), Asheville, NC

Bruce Kelly MD, Staff physician, Blue Mountain Neuro-Medical Treatment Center, Mountain Area Health Education Center (MAHEC), Asheville, NC

Rebecca LaValley, Student, College of Medicine, SUNY Upstate Medical University, Syracuse, NY

Wendy Leonard, MS, LMHC, Vocational Rehabilitation Counselor, Vocational and Educational Services for Individuals with Disabilities (VESID), Syracuse, NY

Elizabeth Liddy, PhD, Dean of the School of Information Studies (i-School), Syracuse University, Syracuse, NY

Gregory Liptak MD, MPH, Professor of Pediatrics and Director of the Center for Development, Behavior and Genetics, Golisano Children's Hospital, SUNY Upstate Medical University, Syracuse, NY

Andrea T Manyon, MD, Professor and Chair, Department of Family Medicine, SUNY Upstate Medical University, Syracuse NY

Alyssa Mayer, Director, Midwest Region 8, Regional Special Education Technical Assistance Support Centers, NY State Department of Education, Rochester, NY

Amanda Miles, Student, LeMoyne College, Syracuse, NY

Regina McConnell, Administrative Assistant, Center for Development, Behavior and Genetics, Golisano Children's Hospital, SUNY Upstate Medical University, Syracuse, NY

Ellen McHugh, lead coordinator, Parent to Parent of NY City

Martha Mock PhD, Institute for Innovative Transitions, Golisano Children's Hospital at Strong Memorial Hospital, University of Rochester, Rochester, NY

Doris Moore, Self-Determination/Consolidated Supports and Services (SD/CSS), NY State OPWDD-DDSO

Christopher Morley, PhD, Assistant Professor & Vice Chair for Research, Department of Family Medicine and Assistant Professor, Department of Public Health & Preventive Medicine, SUNY Upstate Medical University, Syracuse, NY

Christian O'Brien, Library Associate, SUNY Upstate Medical University, Syracuse, NY

Joan O'Brien, MS Ed, RT, Associate Professor and Department Chairperson, Associate Dean, College of Health Professions, SUNY Upstate Medical University, Syracuse, NY

Carsten Oesterlund, PhD, Associate Professor of Information Studies, Syracuse University, Syracuse, NY

Robert Ostrander MD, Family Practitioner, Geneva, NY

Kuni Riccardi, RN, MS, Parent, Advocates Inc. Syracuse, NY

John Reiss PhD, Associate Professor of Pediatrics and of Epidemiology and Health Policy Research, Chief, Division of Policy and Program Affairs, Institute for Child Health Policy, University of Florida, Gainesville, FL

Dr. Susan Scharoun, Associate Professor of Psychology and Department Chair, LeMoyne College, Syracuse, NY

Herb Schneiderman, MD Professor of Pediatrics (retired), SUNY Upstate Medical University, Syracuse, NY

Pat Slaski MEd, Parent and Special Education Teacher (retired), N Syracuse Central Schools

Ruth Small, Ph.D. Professor and Director of the Center for Digital Literacy, School of Information Studies (i-School), Syracuse University, Syracuse, NY

Jeffrey Tamburo LMSW, Supported Employment Program, Enable, Syracuse, NY

Katherine Teasdale-Edwards School Counselor, Special Education Transition Syracuse City School District, Syracuse, NY

Fanny Villarreal, Director of Family & Community Development, P.E.A.C.E. Inc., Syracuse, NY

Amber Villines, Director Mid-State Region 6, Regional Special Education Technical Assistance Support Centers, NY State Department of Education, Syracuse, NY

Sue Wegman, Exceptional Family Resources, Syracuse, NY



Published 2008, Revised 2015
New York State Developmental Disabilities Planning Council

Design by Holly Scherzi Design, Syracuse, NY