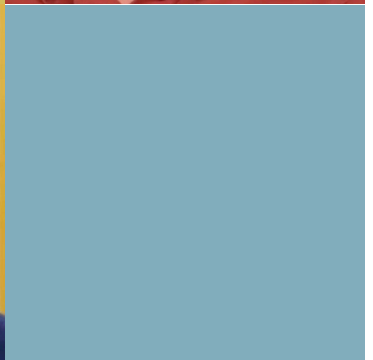
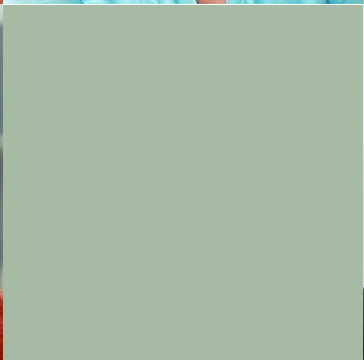
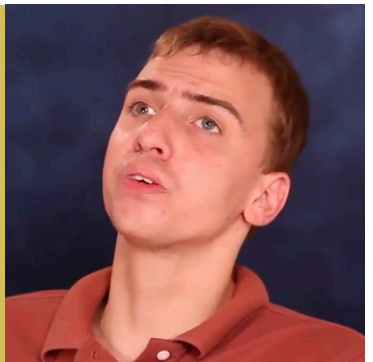


Assuring Access to Quality Health Care for Persons with Disabilities



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Background



“Assuring Access to Quality Health Care for Persons with Disabilities” is a series of six videos designed to prepare health sciences students and practicing health care professionals to serve patients with a variety of disabilities. The idea for creating the videos grew from a desire to expand an effective, in-person training model created and implemented by staff at the Center for Disabilities and Development (CDD) at University of Iowa Hospitals and Clinics. The video training series aims to expand outreach beyond the University of Iowa health sciences training programs. The training modules

were created in partnership with the Midwestern Public Health Training Center and with input from individuals with disabilities, family members and health care professionals. This project was supported by Cooperative Agreement Number NU27DD000019 and NU59DD000949, funded by the Centers for Disease Control and Prevention and jointly administered in Iowa by the Iowa Department of Public Health and the CDD.

The impetus for the in-person health provider training and subsequent creation of online modules was twofold. First, they are an attempt to address the dearth of disability-related training found in standard health sciences training curricula. Second, people with disabilities and their families continually report that there is room for improved communication and accommodation during health care encounters.

For more information about this training series, contact:

University of Iowa Health Care
Center for Disabilities and Development
Health and Wellness Program
Michael Hoenig at michael-hoenig@uiowa.edu

Overview of Training

Assuring Access to Quality Health Care for Persons with Disabilities is comprised of six training modules, available to view at <http://livingwelliowa.org/health-provider-training/>.

The 6 modules are:

- *Disability Training for Future Health Professionals*
- *Disability Training for Practicing Health Care Professionals*
- *Disability Training for Dental Providers*
- *Providing Family-Centered Care*
- *Transitioning to Adult Health Care for Youth with Intellectual Disabilities*
- *Honoring the Diversity of Patients with Disabilities*

Training Goals

- To raise awareness of and address erroneous assumptions that limit access to quality care for people with disabilities and their families
- To equip current and future health care professionals with tools for effectively communicating with and accommodating patients with disabilities and their families
- To improve patient and family-centered care for individuals with disabilities across the lifespan
- To increase the understanding of health care access barriers and associated solutions among individuals with disabilities and their families from diverse backgrounds



Format of Training

Ranging from seven to 38 minutes long, the videos can be shown as stand-alone training modules or as complementary to a panel of individuals with disabilities and family members willing to share their personal health care experiences and suggestions. We encourage you to preview the entire series, then select those clips which best meet the needs of your target audience.

The people with disabilities, family members and clinicians you will meet in the videos are not professional actors. The information they share is based on their personal experiences and articulates ways of improving communication and access to health care for persons with disabilities and their families.

Suggestions for Facilitators

We encourage you to utilize the training modules in combination with a small panel of individuals with disabilities and family members/loved ones. Evaluations from initial trainings indicate that many students value having the opportunity to interact with panel members, hearing their unique perspectives and asking questions while the videos are stopped at predetermined intervals.

When selecting panelists:

- Identify individuals with disabilities or their family members/loved ones who are comfortable sharing their personal experiences.
- If including panelists with hidden disabilities, make sure that they are willing to disclose type of disability and what accommodations work well for them.
- Explain to panelists in advance that the session will include a question and answer period. Instruct them that if they do not know the answer to a question, they should say so and then offer to find the answer. As the facilitator, you should have a plan in place for relaying answers to audience members. If you need help answering audience questions you can contact: michael-hoenig@uiowa.edu.
- Contact Iowa COMPASS (<http://www.iowacompass.org>) to locate Centers for Independent Living and other disability advocacy organizations who are able to refer you to potential panelists living in or near your community.

If you choose to use the video as a stand-alone educational tool, you may wish to ask the students to view the video before class, then facilitate an in-class conversation utilizing the discussion guide which begins on page 4. You will gain valuable feedback during the in-class discussion by asking students to share any assumptions they may have had about people with disabilities before viewing the video(s) as a group or asking students to identify and share two or three ideas they will use from the video(s) to improve their interactions with patients with disabilities and their families.

Finally, we highly value feedback and, whenever feasible, incorporate it into future training offerings. We encourage you to ask students to complete and submit the online evaluation located at: https://uiowa.qualtrics.com/jfe/form/SV_6FqVJz8HLExrr37

VIDEO #1: Disability Training for Future Health Professionals

Synopsis: This video offers a functional definition of disability, includes disability prevalence data, and introduces viewers to individuals with a variety of disabilities who, through a series of vignettes, suggest practical accommodations and communication strategies.

Length: 38 minutes, 29 seconds

VIDEO #2: Disability Training for Practicing Health Care Professionals

Synopsis: Adapted from “Disability Training for Future Health Professionals,” this video offers a functional definition of disability, includes prevalence data, and introduces you to individuals with disabilities and a family member who share best practices for communicating with and accommodating patients with disabilities.

Length: 27 minutes, 28 seconds

Discussion Questions:

1. In their introductions, all individuals with disabilities shared that their hobbies included physical activity. Were you surprised? Why or why not? Why is this important?

Key Points to Cover with Students:

- Being healthy is a realistic expectation for people with disabilities, and physical activity plays a key role in staying healthy.
 - Those who lead a sedentary lifestyle are more susceptible to acquiring secondary disabilities or health conditions.
2. What are some behaviors and health disparities which place people with disabilities at greater risk of acquiring secondary disabilities and health conditions than their non-disabled peers? What public health measures can be taken to address them?

Key Points to Cover with Students:

Examples of behaviors and health disparities include:

- A sedentary lifestyle
- Obesity
- Higher rates of smoking than among those who do not experience disability
- Putting off or not accessing health screenings
- Not seeking medical intervention, often due to factors such as limited finances, few transportation options, and previous negative experiences with health care professionals

Examples of public health measures include:

- Ensuring that initiatives to encourage physical activity among the general population accommodate the needs of individuals with disabilities
- Offering nutrition training for programs which serve individuals with intellectual and developmental disabilities (IDD)
- Educating transportation authorities, disability service providers and support groups on the importance of preventive health care and health promotion

3. What are some mistakes which the health provider (Ann) made throughout the video?

Key Points to Cover with Students:

- Ann did not speak directly to Angie. This is very common and makes patients feel like they are not a part of the health interaction and that they are receiving substandard care. ALWAYS engage the patient, even if he or she is nonverbal and his or her caregiver is the primary source of information.
- Ann was ready to move Angie's wheelchair without her permission. This was problematic because individuals with disabilities often feel that their technology is an extension of themselves. In addition, they may feel insecure without their technology because it offers independence, and any damage requiring replacement may force them to be without the technology for a significant period of time.
- Ann failed to introduce herself to Mike before leading him back to the exam room. Health care professionals should ALWAYS introduce themselves and describe their role to the patient, whether or not the patient has a disability. This is not only common courtesy but serves as a good icebreaker and provides vital information to the patient.
- Ann assumed that Tyler had a guardian. While guardians play a critical role for those whose disabilities prevent them from communicating or making decisions independently, you should not assume that all adults with disabilities have guardians. Most, in fact, do not.
- Ann attempted to finish Tyler's sentence for him. Many individuals with speech impairments find this to be offensive and anxiety-provoking. Be patient and allow individuals with speech impairments to complete their thoughts.

4. What disability accommodations did you observe or learn about during the video?

Some accommodations to point out:

- An accessible exam table benefits patients with physical disabilities
- A screen reader, electronic Braille reader, and talking blood pressure cuff benefit patients who are blind or visually impaired
- The use of sign language interpreters and Video Remote Interpreting benefit individuals who are Deaf
- A variety of clarification techniques can be used to effectively communicate with patients whose speech is difficult to understand

5. Why is the topic of sexuality often ignored by health professionals serving patients with disabilities? What impact might this have on these patients?

Key Points to Cover with Students:

- In the video, Tyler states, “People with disabilities have full lives, and want to experience friendship and love just like anyone else.” William Burr, in a 2011 article entitled “Sexuality of the Disabled Often Overlooked,” asserts:

“The sexuality of people with disabilities, many of whom require varying degrees of assistance to lead fulfilling sex lives, continues to be overlooked, avoided or even dismissed as a component of holistic care because of a longstanding stigma that shrouds disability and sex. ... Doctors and other health care providers often have problems discussing sex with disabled patients, experts on disability say.”¹

Burr’s article quotes a number of persons with disabilities who talk about the importance of leading fulfilling sex lives. Sexuality is a natural part of life and should not be ignored just because an individual experiences a disability.

1. Burr, W. (2011). Sexuality of the disabled often overlooked. *Canadian Medical Association Journal*, 183(5), E259-E260.

VIDEO #3: Disability Training for Dental Providers

Synopsis: This video utilizes the first-hand accounts of dentists, individuals with disabilities and a family member to address topics such as referral guidelines, physical accessibility requirements for dental practices, and strategies for communicating with patients experiencing a variety of disabilities.

Length: 28 minutes, 58 seconds

Discussion Questions:

1. Do dentists need to be specially trained to serve patients with disabilities?

Key Points to Cover with Students:

- In many cases, special training is not required. The important things are to use common sense and provide quality care.
- Dentists should not feel pressure to be “instant experts” on disability. It’s important, though, to become familiar with patients’ presenting conditions.

2. What are some techniques dentists can use to determine whether to refer a patient with disabilities to a specialist?

Key Points to Cover with Students:

- Use your professional discretion.
- Assess the ability of your practice to meet the patient’s needs.
- Start by providing preventive care. This will give you the chance to determine if the patient has additional needs which would be better addressed by a specialist.

3. What are some steps dental practices can take to become “disability friendly?”

Suggestions for Students:

- Provide an ample number of accessible parking spaces near the front door.
- Adopt a “person-first” philosophy. Remember that disability does not define the patient, and no two patients, even with the same diagnosis, are alike.
- Develop positive professional relationships with patients with disabilities, just as you do with all patients.
- Develop strong professional relationships with caregivers of children and of adult patients who cannot speak for themselves. These caregivers will serve as your primary source of information.

4. What are some strategies which dentists and dental practices can use to ensure optimal communication with patients with disabilities?

Suggestions for Students:

- Set up patient profiles which will allow inclusion of accommodations such as sign language interpreters or accessible materials.

- When communicating with patients who are Deaf or hard of hearing, face them, speak in a normal speed and tone, and do not exaggerate your speech with excessive movement of your lips.
- Provide visual cueing for patients who find it difficult to understand verbal instructions.
- Provide verbal descriptions of procedures and tactile descriptions of equipment to be used for patients who are blind or visually impaired.
- Ask patients how they will incorporate your recommendations into their daily routine (teachback).

5. What are some common practices for reducing anxiety during a dental visit?

Suggestions for Students:

- Minimize or eliminate sensory distractions such as fluorescent lighting, fragrances, and loud sounds.
- Utilize distraction techniques such as bite sticks, weighted blankets or gowns, and papoose boards. Rely on parent/caregiver guidance when determining whether to use these techniques with adults.
- Create a welcoming environment. “Extras” like pictures on the ceilings and a designated “movie room” can go a long way toward making the patient feel comfortable.

VIDEO #4: Providing Family-Centered Care

Synopsis: This video offers the perspectives of three parents of children and young adults with disabilities on such topics as impact of diagnosis, care coordination, and the role of the family in facilitating access to quality care.

Length: 23 minutes, 57 seconds

Discussion Questions:

1. Sarah emphasizes the importance of care coordination.
What care coordination strategies did you learn about?

Possible Responses:

- Ensure that all health providers across disciplines are “on the same page,” especially at discharge.
 - Ensure that out-patient services such as occupational, physical and speech therapy are in place at the time of discharge. This will save the family from a difficult task during an extremely chaotic time.
 - Document all patient interactions and procedures to prevent duplication of service and avoid “re-inventing the wheel.”
 - If you do not feel that you can answer a question or treat a condition, refer the family to a specialist. Always inform the family that you will be making the referral.
2. All three parents stressed the importance of including the child in all health care interactions, even if s/he is nonverbal. Why do you think engaging the patient is so important? How might the parents/caregivers feel if all interaction is directed toward them?
 3. Paula says, in reference to her son Aaron, “We’re doing things with him, not to him.” Why do you think this distinction is so important to Paula and to Aaron?
 4. Paula and Sarah both explain that, following extensive research, they brought treatment recommendations to their physicians for consideration. Both expressed gratitude that their physician ultimately agreed to pursue the treatment options. How would you decide whether to proceed with a treatment recommended by a patient’s family? What factors would influence that decision?
 5. Paula explained that Aaron’s transition from the pediatric to adult health care system went much more smoothly than expected because the family’s long-time pediatrician referred the family to a new physician and arranged a visit with all parties present prior to his retirement. Why do you think this “handoff” of care proved to be successful?
 6. Sarah commented that health care professionals should keep hope alive, even when a child’s prognosis is dire. When delivering such a prognosis, how do you balance the desire to support the family with the reality of the situation?

VIDEO #5: Transitioning to Adult Health Care for Youth with Intellectual Disabilities

Synopsis: This video offers a view of the shift from pediatric to adult health care through the eyes of an adolescent with Down syndrome and her mother.

Length: 6 minutes, 42 seconds

Discussion Questions:

1. Sydney tells us that finger pokes, shots, and not knowing what the doctor is going to do are things which make her nervous about medical appointments. As a health care professional, what might you do to ease her anxiety before and during the appointment?

Suggestions to Consider:

- As part of an after-care plan, ask the patient and his/her caregiver how you can help prepare for future visits.
 - Offer a picture schedule in advance of the procedure to describe what will happen.
 - Administer shots and finger pokes in the exam room rather than the lab.
 - Use numbing gel.
2. Many 16-year-olds prefer to see their health care provider without a parent present. Because of Sydney's intellectual disability, she requires her mother's assistance to "translate" concepts and instructions during the appointment. As a health care professional, how would you balance Sydney's growing need for independence with the need to ensure effective provider/patient communication?
3. Kelly describes several ways in which Sydney is taking more responsibility for her health care. As a health educator, how would you facilitate Sydney's continued growth in this area?
4. Kelly explains that as a young mother, she was afraid to ask questions. As a health care professional, what can you do to encourage your patients and their families to ask questions about their care?
5. Kelly described a time when she left a health care provider because she did not feel that the provider listened to her or respected Sydney. What can you do to ensure that families of children with disabilities feel respected?

Suggestions to Consider:

- Remember that individuals with disabilities are PEOPLE FIRST. They are people who happen to experience disability, but they are not their disability.
- Actively listen to the family's concerns.
- Be patient!
- If you don't have all the answers, consult specialists.

VIDEO #6: Honoring the Diversity of Patients with Disabilities

Synopsis: This video is designed to assist health care professionals in providing culturally competent health care to individuals with disabilities/special health care needs and their families. Two family members representing diverse cultures share personal insight on how race, culture and ethnicity influence the treatment of patients with disabilities and provide recommendations for eliminating preconceived notions, assisting families in navigating the health care system, and optimizing communication.

Length: 14 minutes, 53 seconds

Discussion Questions:

1. Arianna describes feeling pre-judged as “a single black woman who doesn’t know very much,” while Karin tells us that she was labeled as a “bad parent” because of her child’s behavior. These are examples of implicit bias. What steps are you willing to take to ensure that your patients do not experience implicit bias?
2. Karin shares that when she moved to the United States from Brazil, she did not know what questions to ask, what services were available, and which health care providers would be part of her daughter’s team. What proactive steps are you willing to take to ensure that all patients, especially those unfamiliar with services available in the United States, have the information they need to make informed decisions?
3. Both Karin and Arianna describe culturally-related stigma associated with diagnosis of a disability or special health care need. Karin points out that parents may come to you as a health professional at any number of stages ranging from guilt to shame to self-pity. What proactive steps are you willing to take to understand cultural attitudes toward disability and to provide a safe environment for families to discuss their feelings and concerns?
4. Arianna’s health care team persisted in asking, “Where’s Dad?” Ultimately, she inferred the team’s assumption that Dad was not involved in his family’s care. How could the team have approached the question of Dad’s involvement differently?
5. Karin tells us that, in Latino cultures, the advice of family members may carry more weight than advice from health care professionals. What steps can you take to proactively involve members of the patient’s extended family in health care decisions?
6. Arianna describes health care providers being surprised when they see her outward forms of self-expression (tattoos, piercings and a head wrap). What will you do going forward to communicate acceptance of personal self-expression?