



Fact Sheet

Providing Excellent Care for Patients with Developmental Disabilities

Who are patients with Developmental Disabilities (DD)?

They are people who have significant lifelong disabilities: intellectual, physical, developmental and sensory disabilities. These can affect many areas of life especially language, learning, mobility and independent living. Some examples are people with Down syndrome, Autism Spectrum Disorder, Cerebral Palsy, Spina Bifida, etc.

Why is communication training important?

Reception, ancillary and support staff are often the first to encounter patients as they enter the healthcare system. Many healthcare workers are not very familiar with caring for patients with DD, and received little, if any, training in DD during their educational programs. This unfamiliarity can result in healthcare workers having inaccurate beliefs about patients with disabilities, and apprehension when caring for them. The stigma surrounding patients with disabilities can cause many barriers for patients when accessing healthcare. Staff members can hold negative attitudes, and patients with DD often report experiencing negative behaviors from office staff. DD has been found to be a risk factor for dissatisfaction and disappointment with healthcare encounters. As reception, ancillary and support staff are often the first impressions of the health system, education and training for effective communication with patients with DD is extremely important.

Remember...

You may be the initial interface of the healthcare system for many patients – we can further help reduce dissatisfaction and disparities for patients with DD by utilizing effective communication strategies, adapting the clinical environment and addressing logistical barriers. Through these practices, we can X-CEL by providing excellent (X) care to patients with DD through improved Communication (C), Environment (E) and Logistics (L).



Resources for Patients

Education for Lifelong Health Series: How Do I Talk to My Doctor?

http://flfcic.fmhi.usf.edu/docs/FCIC_EFLH-6-TalkingToMyDoctor_Fact%20sheet.pdf

My Health Report

http://flfcic.fmhi.usf.edu/docs/FCIC_My_Health_Report_Fillable.pdf

My Health Passport


http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf



X-CEL

Communication:


- be patient
- speak the same language
- ask for clarification
- encourage participation



X-CEL

Environment:


- reduce noise
- eliminate odors
- steady lighting



X-CEL

Logistics:

- flexibility in scheduling
- advance warning for changes
- maximize the appointment
- first/last appointment slots



Tips for Improving Communication

- Some people with disabilities have difficulty with speech – allow extra time, don't speak for the person or use a family member or caregiver as a surrogate for communication.
- Some have difficulty with comprehension – do not use medical jargon or abbreviations, just straightforward words.
- Don't pretend to understand when you haven't – be honest!
- Tap into the expertise that patients and caregivers have regarding their disability.
- Encourage better preparation for appointments by using tools like "How Do I Talk to My Doctor?"
- Encourage use of "My Health Passport" or "My Health Report" to give the healthcare professionals more specific information about their disability, and how best to offer assistance.
- Do not avoid or skip elements of the office encounter because you think they may be too difficult or too complicated (eg. taking height/weight, measuring vitals, etc.)

FOR MORE INFORMATION

<https://vkc.mc.vanderbilt.edu/etoolkit/general-issues/communicating-effectively/>

Tips for Adapting the Environment

- Some people with disabilities have difficulty in adjusting to a new environment. Suggest that people make a visit to see the facility before their actual appointment.
- Some are very sensitive to their environment. Noises, odors and bright lighting can be overwhelming. If possible, have a quiet area or room to wait in – or attempt to schedule patients with DD as first or last appointments of the day (when the office may be less crowded).
 - » **Noises** – Have television on in the background at a volume that is not distracting and use close captioning.
 - » **Odors** – Limit the use of strong air fresheners, flowers with strong fragrances, and encourage use of low-odor cleaning supplies.
 - » **Lighting** – Make sure light-bulbs aren't flickering or excessively bright.
- Routinely re-assess the accessibility of your office, waiting room, and exam rooms from the perspective of a patient with a disability.

FOR MORE INFORMATION

http://fpg.unc.edu/sites/fpg.unc.edu/files/resources/other-resources/NCODH_RemovingBarriersToHealthCare.pdf

Tips for Addressing Logistical Issues

- Some people with disabilities have difficulty with transportation and might need to rely on others or public transportation services.
- You can help by
 - » Being as flexible as possible to offer appointments that fit public transit schedules.
 - » Giving as much advance warning as possible if an appointment needs rescheduling.
 - » Maximize what can be done at one appointment rather than having multiple appointments.
 - » Consider making appointments first or last of day to allow for more flexibility.



You may be the initial interface of the healthcare system for many patients – use X-CEL principles to make a great impression!

VanZant, S., & Perkins, E. A. (2017). *Providing Excellent Care for Patients with Developmental Disabilities*. Florida Center for Inclusive Communities.



For more information about this or other FCIC health resources, contact Dr. Elizabeth Perkins at eperkins@usf.edu • 813-974-7076

View the X-CEL video, and other FCIC health resources at XCEL.flcic.org