



Improving Communication with Patients who have Intellectual and Developmental Disabilities

Physicians

FACT SHEET

Patients with Intellectual and Developmental Disabilities (IDD) are recognized as an underserved population that experience significant disparities in healthcare.¹⁻³ As medicine continues to advance, patients with IDD are living longer, experiencing more secondary and chronic illnesses, apart from their disability, and are seeking treatment from primary care providers to manage these conditions.³⁻⁶ Individuals with IDD experience poorer health outcomes, and are at greater risk of disparity and poorer social health determinants including:^{1,5}

- Complex health conditions
- Decreased cancer screenings and preventive services
- Poorly managed chronic diseases
- Undetected vision problems
- Additional mental health problems
- Limited access to health care services
- Being unemployed
- Under educated
- Lower income

Individuals with IDD have a greater need for healthcare; however, disability has been found to be a risk factor for dissatisfaction and disappointment with provider encounters.⁷ One way in which medical encounters can be improved is through better communication practices. Effective doctor-patient communication is essential for establishing strong patient relationships and working to eliminate health disparities faced by individuals with disabilities. However, communicating with patients with IDD can present various challenges to the physician. Patients can have dysarthria, low literacy, or be non-verbal. It is important to remember that there is significant diversity within diagnoses, e.g., people with cerebral palsy may or may not have intellectual disability. Regardless of the patient, or their diagnosis, it is important to remember that the basis of communication with patients with IDD, or any patient, is to treat them with dignity and respect.

Building Rapport:

- Always address the patient first, and orient yourself in a way that allows you to maintain eye contact with the patient.
- Irrespective of IDD, it is always important to use age appropriate tone and language (be careful not to allow your communication to be misconstrued as patronizing).
- Always begin your interview by explaining the purpose of the encounter and establish communication preferences. The patient may require the use of assistive communication devices or interpreters.
- Practice triadic communication – always speak to the patient first. Use their caregiver to help facilitate communication, not as a surrogate for communication.

** Remember, appointments for patients with IDD will most likely take more time. It may be helpful to schedule appointments at the beginning or end of the day when your schedule has more flexibility.

History Taking:

- Explain the purpose of your questions.
- Be sure to focus on the patient's chief complaint – do not focus solely on their disability.
- Ask questions directly to the patient.
- Allow the caregiver to fill in information or provide additional details that the patient may not be able to give.
- Take advantage of the knowledge/insight that the individual/caregiver can provide about their health and disability.

** Prompt patient and caregiver to come to the appointment prepared. Ask them to bring copies medical records, their medication list and a list of questions they may have. This will speed up the history taking process and allow you more time to speak with the patient about their concerns.



During the Physical Exam:

- In some cases it may be necessary to adapt specific physical exam maneuvers. Do not avoid any component of the physical exam that you think may be difficult to complete or hard for the patient to comply with – patients and caregivers expect the same kind of treatment and attention. For instance, you may need to adapt the positioning of some maneuvers to accommodate patients who are wheelchair users.
- Offer assistance when you feel it is needed; wait until that offer is accepted before stepping in.
- Explain, and demonstrate when possible, during each step of the physical exam. It may be helpful to use a model, or demonstrate what you will be doing on yourself before starting (i.e. where you will be placing the stethoscope, or how you will be palpating the patients stomach during an abdominal exam).
- Do not avoid questions/screening for sexual health issues. Many people with IDD do have intimate sexual relationships.



Assessment and Diagnosis:

- Do not assume that there is a correlation between symptoms and disability – patients with IDD have many of the same secondary and chronic conditions as the general population.
- Beware of ‘diagnostic overshadowing’. Often, symptoms are automatically attributed to the patient’s disability. This is especially true of behavioral and developmental problems.⁴

Treatment and Plan:

- Explain your findings in appropriate terms.
- Ensure understanding of both the patient and the caregiver. Avoid medical jargon and attempt to use clear, concise medical language.
- Provide patients and caregivers with appropriate materials to take home with them. Try to use adapted literature that uses visual aids and is in “easy read” format.
- Easy read materials are written at an elementary or middle school reading level, include visual aids and are written in clear and concise language.

Quality Patient Care

Quality patient care begins with you; as this patient’s physician you will play a large role in ensuring they receive appropriate care in all aspects of life – not just for their disability. With such diversity within patients with IDD, it is impossible to be an expert on every syndrome and symptom. Allow the patient and caregiver to share their knowledge about their condition with you. Good doctor-patient communication is essential to providing quality care to every patient. Remember, effective communication begins with dignity and respect, regardless of the patients’ cultural background or abilities.

For more information, and to further build your knowledge about IDD and providing quality care to patients with disabilities, seek out CME courses focused on these topics. Organizations including the American Academy of Developmental Medicine and Dentistry (www.aadmd.org), and the American Association on Intellectual and Developmental Disabilities (www.aaid.org) offer useful information. For a range of free materials for patients with IDD, visit FCIC health resources website (<http://flfcic.fmhi.usf.edu/program-areas/health.html?tab=2>).

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

Curbside Consultation

Patients with Disabilities: Avoiding Unconscious Bias When Discussing Goals of Care

Commentary by CLARISSA KRIPKE, MD, FAAFP, *University of California San Francisco, San Francisco, California*

Case scenarios are written to express typical situations that family physicians may encounter; authors remain anonymous. Send scenarios to efjournal@aafp.org. Materials are edited to retain confidentiality.

This series is coordinated by Caroline Wellbery, MD, Associate Deputy Editor.

A collection of Curbside Consultation published in AFP is available at <http://www.aafp.org/afp/curbside>.

Case Scenario

A 58-year-old nonspeaking patient with an intellectual disability was admitted to the hospital for cholecystitis. He also had a well-controlled seizure disorder, secondary parkinsonism from medications he was no longer taking, and diabetes insipidus. His surgery was uncomplicated. Because of the patient's underlying disability and need to drink a high volume of water to maintain sodium balance, his recovery proceeded slowly. Six days after surgery, his ability to swallow had partially recovered, but he was still requiring fluids and food through a nasogastric tube.

The hospitalist took the initiative to invite hospice representatives to a team meeting to discuss goals of care. He recommended a transfer to hospice care because of what he called, "The patient's suffering and risk of aspiration." Hospice was willing to admit him based on the referral, and his family initially agreed. However, when the hospitalist was confronted with questions from the patient's primary care physician about the terminal diagnosis and evidence of suffering, it became clear that the recommendation for hospice was based on the hospitalist's misperception of the patient's quality of life and pressures to advance discharge, rather than on specific medical indications. The patient was back home within a couple of months, eating his favorite foods, and he recovered to his previous baseline function. He has returned to his day program and activities. What could the hospitalist have done better to support and expedite this outcome?

Commentary

False assumptions about patients' quality of life can affect prognosis, the treat-

ment options that we present, and the types of referrals that we offer. In this case, the physician equated complex disability with terminal illness. This common confusion can result in premature withdrawal of life-preserving care. Disability is not a disease. Persons with physical, mental, and cognitive disabilities can and do live rich, full lives. They are often healthy, even if they need support for basic activities of daily living. If well managed, secondary conditions such as aspiration, pressure sores, and osteoporosis can be prevented or minimized. With appropriate services and accommodations, persons with disabilities can make decisions, have relationships, and contribute to their community. This outcome is more likely when they are welcomed, supported, and valued. Despite a high prevalence of chronic medical conditions, the life expectancy of persons with developmental disabilities approaches that of the general population.¹

Physicians may mistakenly extrapolate high rates of significant functional decline observed in older patients after hospitalization to younger patients with complex disabilities. Younger patients with disabilities, however, are often healthier and more resilient than older patients, and their prognosis is often better after an acute illness.

This patient is recovering slowly from an acute, temporary illness. The physician's concern for aspiration, although understandable, hardly warranted transfer to hospice. Aspiration is a preventable secondary condition that can be effectively managed through diet texture, posture, careful supervision, and assistance with feeding. Falsely labeling a person with a disability as terminally ill can create a self-fulfilling prophecy, especially for those who need long-term support to thrive.²

Curbside Consultation

Table 1. Common Communication Pitfalls When Discussing Goals of Care for Patients with a Disability

<i>Unconscious bias</i>	<i>Supportive communication</i>
<p>Pity</p> <p>"This poor, unfortunate patient suffers from..."</p> <p>"I understand that you don't want to be dependent and a burden to your family."</p>	<p>Respect</p> <p>"Mr. Smith is a 56-year-old man who uses a wheelchair and volunteers as a patient advocate. He presents with..."</p> <p>"Adjusting to new functional limitations takes time. Maybe it would help if you hear directly from persons living with disabilities."</p>
<p>Abandonment</p> <p>"There is nothing we can do."</p> <p>"Call me if your pain is out of control."</p>	<p>Maintaining and deepening connection</p> <p>"Although the risks of this treatment outweigh the benefits in your case, I look forward to seeing you regularly and providing you with care. What are your hopes, needs, and fears?"</p> <p>"I'll call you to check on your pain. In the meantime, I'll consult with our palliative care team. There are support groups and mindfulness-based stress reduction classes that might interest you."</p>
<p>Misleading prognosis</p> <p>"You have less than six months to live."</p>	<p>Sharing expertise and uncertainty</p> <p>"Nobody knows for sure how long you have to live. It is especially difficult to make accurate estimates in persons with underlying disabilities. Most people with your condition live months rather than years."</p>
<p>Institutionalization</p> <p>"As your condition progresses, you may need to move to a nursing home."</p>	<p>Home- and community-based services</p> <p>"I'm going to refer you to our social worker, who can help you access extra help and home modifications so you can enjoy this time with friends and family."</p>
<p>Interventions without context</p> <p>"Would you want to live on a machine if you could never be taken off it?"</p> <p>"Would you want to be kept alive with a feeding tube?"</p>	<p>Information about person-specific goals, risks, and benefits</p> <p>"You have weak muscles that are affecting your swallowing and breathing. We can reduce the risk of aspiration pneumonia, improve your nutrition, and give you more energy with a tube for feeding and a home ventilator. It might help you to hear the stories of other people with neuromuscular disabilities who are living well on a home ventilator."</p> <p>Patients may appreciate help exploring stories online from other persons with neuromuscular disabilities. Examples of materials that show diverse representations of persons living with disabilities include http://dearjulianna.tumblr.com/ and https://www.youtube.com/watch?v=UfaGoTVWvMo.</p>
<p>Dehumanization</p> <p>"Alzheimer disease will slowly rob your mother of her memory and dignity."</p>	<p>Inclusion</p> <p>"Let me share some tips on how to be a good friend or family member to a person with Alzheimer disease."</p> <p>A brief video with helpful suggestions for friends and family members is available at https://www.washingtonpost.com/video/national/health-science/heres-how-to-practice-good-alzheimers-etiquette/2016/05/30/5c13a6a6-25cc-11e6-8329-6104954928d2_video.html.</p>
<p>Devaluing the life of a vulnerable person</p> <p>"Are you sure you want the surgery and treatment even though they won't cure your disability?"</p>	<p>Supporting to maximize potential</p> <p>"We'll be sure to get physical therapy staff involved right after the surgery to prevent any loss of strength or mobility while you are recovering. Let's arrange extra help with managing your activities of daily living in the hospital and when you go home."</p>
<p>Stealing hope</p> <p>"That's not realistic."</p>	<p>Sharing hope and realistic planning</p> <p>"I hope that too! Wouldn't that be great! Let's keep that goal in mind and also make a plan to prepare for things that are likely to come up."</p>
<p>Disrespecting autonomy</p> <p>"Who makes her medical decisions?"</p> <p>"Does she have pain?"</p>	<p>Supported decision making</p> <p>"Do you want to name a trusted supporter to help you make medical decisions?"</p> <p>A resource with materials on supported health care decision making is available at http://odpc.ucsf.edu/supported-health-care-decision-making.</p> <p>"How can we communicate best? What kinds of things can I do that will work for you?"</p> <p>Physicians can offer an approach to communication that reflects the principles outlined in this handout: http://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf_docs/wiw%20non%20trad%20communicators%20final_0.pdf.</p>

Physicians should be careful to avoid making assumptions about patients' quality of life, especially those who rely on external assistance. They should also avoid reinforcing patient or caregiver fears and misconceptions about living with disability. For example, in one study of hospitalized able patients with serious illnesses, more than one-half of respondents believed that some health states were the same as or worse than death, including incontinence, requiring a breathing tube, relying on a feeding tube, or needing care from others all of the time.³ But many persons with developmental disabilities have required these supports since birth, yet still have meaningful lives.⁴ After a period of adjustment, those who live with acquired, chronic illness and disability also typically rate their own quality of life significantly higher than their physicians and caregivers do. Self-reported quality of life for persons with disabilities is not significantly different than that of the general population.⁵⁻⁷

Instead of sharing decision making and respecting autonomy, physicians may unconsciously project their own attitudes onto the patients they serve through how they frame informed-consent discussions.⁸ Table 1 includes examples of common communication pitfalls with alternative phrasing and resources. Being aware of unconscious biases will help physicians better support their patients during stressful times.

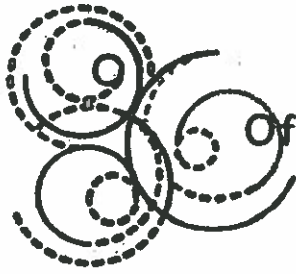
The attitudes and beliefs of physicians can interfere with the care patients want or need.⁹ We can improve access by reassuring patients that no matter what choices they face, we will care and advocate for them.

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Office of Developmental Primary Care

Improving outcomes for people with developmental disabilities

What I Wish My Doctor Knew About People who Accompany Us to OUR Medical Appointments

Medical Alert

- We are your primary patient.
- Bringing an attendant is not an indication of a lower level of competence.
- Educate your office staff and medical assistants.
- Obtain a basic understanding of the relationship that we have with our attendant.
- Our attendants may request additional help when assisting us with physical activities.
- Evaluate the needs and capabilities of our primary support system.
- Acknowledge and respect our privacy.
- Don't worry if we come to our appointment alone.

Background

Some of us with physical and cognitive disabilities may come to a medical appointment with another person to help us during our visit. This person may be a paid attendant, a staff member from an assistive living facility, a family member, or a friend. These health advocates can serve a variety of important functions during the appointment, including transporting us to your office, filling out paperwork, and helping with physical tasks such as undressing and climbing onto an exam table. They can also facilitate our communication attempts. Each advocate will serve a different and unique role depending on our specific needs.

There are some things we would like you to remember when we visit your office with another person.

Acknowledge our Autonomy

First, we are your primary patient. Please avoid such phrases as, "How is she doing?" or "Where does he feel the pain?" Acknowledge the fact that we live inside our bodies. Try speaking directly to us. Many of us are aware of changes in our bodies and can answer your questions.

Don't Make Assumptions

Please don't assume that the presence of a personal attendant or an individual's diagnosis is an automatic indication of competence. It may be easier and quicker to communicate with the attendant or family member, but we will not feel empowered or respected as your patient.

Train Your Staff

Your office staff and medical assistants often set the tone for our visit. Please demonstrate and teach everyone on your staff respectful ways of communicating with patients who have disabilities. They should remain patient and maintain a dialog with us. Other examples of helpful tasks might include: moving furniture out of our path of travel or assisting us in filling out paperwork when needed.

Understand Our Relationship

Sometimes it might be helpful and necessary to include our attendant or health advocate in the conversation. This is usually fine, especially if you have our consent. If possible, try to get a feel for the nature of our relationship. Is this person actively involved in our lives? Do they appear to treat us with dignity and respect? Are they advocating on our behalf? Is our best interest their top priority?

Evaluate Our Support System

When prescribing an at-home treatment or a lifestyle change, it can be useful to evaluate the needs and capabilities of our primary support system. Will the additional treatment have a direct impact on our attendant? If they are expected to assist us with this new task, are they willing and able to meet any physical or psychological requirements? If not, is a referral or alternate plan needed?

Ask if Extra Help is Needed

Our attendants or family members can be very helpful with certain physical tasks, but they may not be able to do everything. For example, they may need help with high and awkward transfers or other unusual physical activities.

Respect Our Privacy

We may not wish to discuss certain issues with our paid attendant or family member in the room. Please ask us if there is anything we want to discuss in private. For those of us who have trouble with verbal communication, provide us with a secure email address or another channel of private communication.

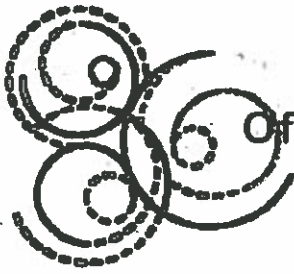
We May Come Alone

Don't be surprised if we sometimes show up to our appointment without anyone else in tow. We may not always need or want help. We can figure out the logistics of our solo appointments with you.

Written by Melissa Crisp-Cooper. Used with permission. Created 6/20/14



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Office of Developmental Primary Care

Improving outcomes for people with developmental disabilities

What I Wish My Doctor Knew About Me as a Person with Sensory Sensitivities

Medical Alert



- **ASK whether lights, sounds, smells, are OK.**
- **Make lighting dim or subdued natural – no flicker or glare.**
- **Quiet please – no slams, hums, or beeps.**
- **Remove ALL scents (perfumes and in deodorant & soaps).**
- **Please, no cold, rough surfaces, or alarming touch.**

Background

Almost half of us on the autism spectrum are painfully sensitive to sensations of one kind or another. This can lead to disorienting or debilitating sensory overload, shutting down our ability to communicate, and making a routine visit to a doctor or hospital nightmarish. Fortunately, there are many things *you* can do to make *our* visit better.

First, please ask if anything in the room is causing discomfort, and read any notes I have written for you. Be aware that many of us have difficulty identifying and stating what is bothering us. By adulthood, most of us have a growing awareness of what causes discomfort and we can tell you. Others of us, though, know, but can't easily describe what's awry. We need you to be patient. Ask me whether it would be easier to communicate in writing, or in less light. Here are some common problems and what can help.

Reduce the Intensity of Sensations

Light: It's too bright, too fake, and flickers too much.

Please use subdued natural light where possible and avoid bright artificial lights. Where possible reduce: point lights in the dark, glaring lights, flickering images on monitors, fluorescent lights, whirling fan blades and garish colors or patterns. Window blinds that make bright lines are bad. Also, I'm not a shifty malcontent: it's just that sometimes eye contact with strangers feels like staring into the sun!

Sound: I hear everything.

Please don't make sudden or unexpected noises. Where possible, reduce high-pitched sounds; constant hums (as from refrigerators); muffled voices through walls; non-natural light sounds (like ticks and beeps); jumbled sounds that are hard to separate; the TV in the waiting room next door. Any of these can be excruciating. Volume is not always the issue: *Small* non-natural sounds can be more painful than loud ones.

Smell: Your scents make no sense.

Many of us would rather smell any natural odor than any perfume. The smelliest bathroom is better than the “freshest” air freshener. Perfumed detergent residues on clothing, hand soaps, hand and face lotions, mouthwash, colognes, and deodorants – all those scents overwhelm us at best and make us ill at worst. Let there be fresh air!

Taste: The medicine tastes better without the fake candy flavor.

Try a natural flavor is one if absolutely needed. Texture can be a problem, too: Is the medicine available in another form? I may not tolerate certain tastes, like citrus. This can cause nutrition problems as well. Telling me to “Eat more vegetables” doesn’t help if the taste makes me nauseous.

Touch: Don’t stab me with that cloth!

Non-soft fabrics, seams and labels, cold instruments, unexpected touch and sometimes any touch at all – all of these can be unbearable. Please keep the room at a moderate temperature.

Reduce the Number of Sensations

I don’t do “sensory multitasking” well. If you want to communicate with me it can help to reduce the number of sense *modes* involved. Here are some strategies to do this:

Communicate without sound.

- In writing – via paper, iPad, keyboard or the like.
- With pictures, if it feels welcome.
- In silence I don’t have to interpret your vocal intonation or control mine.



Communicate without light.

- Through quiet speech in near-darkness.
- In darkness I don’t have to interpret your body language and facial expression, or regulate mine. On the other hand, I may need some light to see your lips, to help me understand what you’re saying.

Reduce the “bandwidth”.

- Allow room for silence in conversation.
- Communicate one-on-one, not in groups.
- Speak calmly with fairly even tone and without condescension.

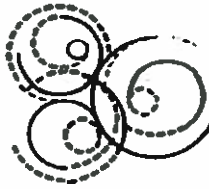
All of these suggestions will be wrong for some people. Improvise!

Sensitivities can vary. Some days I can tolerate what on other days I cannot. I’m usually more sensitive when I feel bad – like when I’m sick! I am not making the sensitivities up: It means I change daily like most people, and the effects are cumulative. Very often *I am at the mercy of my environment*. Please help remove the causes of the debilitating sensations! I am grateful for your aid.

I know that the world cannot always adjust to my sensory needs, and sometimes I just mask as much as I can. One other way you can help is to accept and support my personal accommodations, even though they may look strange. (See picture above.) I am a person whose senses are exquisitely sensitive. The same sensitivities might let me see in the dark and be an extraordinary audio tech.

Thank you for your help and understanding!

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Evaluation of Behavior Change

In people with communication disorders, illness typically presents as a change in behavior or function. Behavior can be a form of communication. People with communication disorders can usually give important information about their health. They may need supports such as visuals, choices, or access to augmentative and alternative communication. Any patient with a change in behavior or function should receive a medical evaluation.

The **HURTS** mnemonic provides a differential diagnosis of the most common medical causes of behavior change in people with developmental disabilities.

Head, including cervical spine: migraines, hearing, vision, dental, and neck injury

Urinary tract: kidney stones, urinary tract infections, and obstruction

Reflux and gastrointestinal problems

Thyroid and trauma

Seizures and side effects of medication: seizures can present as inattention, behavioral tics or emotional lability

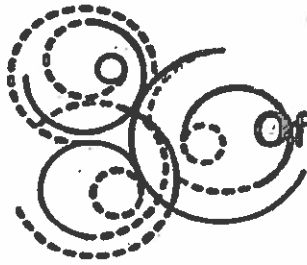
Behavior changes can also signal:

- Abuse or other stressors
- Escape or avoidance of demands
- Increase in arousal or self-stimulation
- Means of accessing preferred activity or objects
- Mental illness
- Need for social attention
- Pursuit of power and control
- Reduction of arousal that leads to anxiety
- Sensory problem: vision, hearing or sensory integration
- Substance abuse
- Unrecognized pain or discomfort

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Improving outcomes for people with developmental disabilities

Managing a Behavioral Crisis

Safe

- Introduce yourself
- Use plain, clear, concise words
- Explain your intentions
- Avoid sudden touch or grab
- Formally end your contact, e.g. "I am going to leave now."
- Wait it out (Don't just do something, stand there)

Calm

- Control your affect and behavior
- Redirect attention to something concrete, factual, and non-emotional
- Stand back to avoid getting injured
- Be aware of your position in relation to person (flight is better than fight)
- Remove objects that can be weaponized and extra people

Affirmation

- Set clear limits
- Minimize distractions
- Use kind, encouraging words
- Repeat a positive mantra
- Allow breaks

Routine

- Redirect to task at hand
- Cue person
- Provide visual support
- Be consistent

Empathy

- Ask what happened to you; not what is wrong with you
- Offer another way to get need met
- Avoid repeatedly disagreeing

Develop intervention plan

Lipsky, D, Richards, W. Managing Meltdowns Using the S.C.A.R.E.D. Calming Technique with Children and Adults with Autism. 2009. Jessica Kingsley Publishers. London.

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