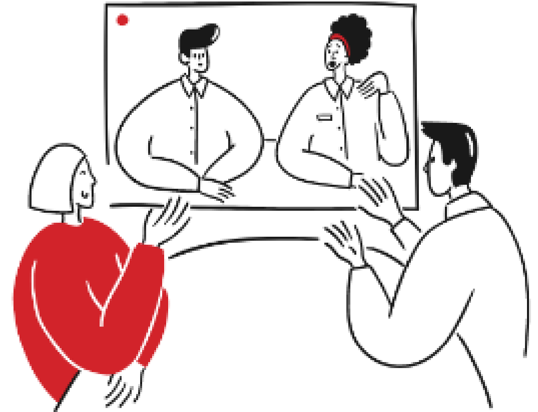
Improving Care for Patients with Intellectual and Developmental Disabilities (IDD): Foundations and Practical Communication Strategies for Community Health Centers

March 25, 2026

HRSA Funding Acknowledgement:
This training is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award to CHCANYS' New York State Primary Care Association (NYS-PCA) totaling $1,709,057.00. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit HRSA.gov.

Housekeeping

- Welcome!
- Let’s get to know each other - Take a moment to introduce yourself in the chat!
- **Please change your name to your full First and Last Name**
- **Please add your Health Center/Organization Name next to your name!**



Speaker

Dr. Michelle Catanzarite

Chief Medical Officer,

Achievable Health

IMPROVING CARE FOR PATIENTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (IDD):

FOUNDATIONS AND PRACTICAL COMMUNICATION STRATEGIES FOR COMMUNITY HEALTH CENTERS

MICHELLE CATANZARITE, MD
ACHIEVABLE HEALTH

MCATANZARITE@ACHIEVABLE.ORG

INTRODUCTIONS

- Achievable Health
  - FQHC in Culver City
  - Co-located with Westside Regional Center
  - Experience and focus caring for people with Intellectual and Developmental Disabilities
- Michelle Catanzarite, MD- Chief Medical Officer for Achievable Health
- I have no financial conflicts to disclose

LEARNING OBJECTIVES

By the end of the session participants will:

- Define intellectual and developmental disabilities (IDD) and describe common types of IDD encountered in primary care settings.
- Recognize common behaviors associated with IDD and distinguish them from behavioral responses related to unmet needs, environmental stressors, or communication barriers.

LEARNING OBJECTIVES

- Apply practical strategies for effective communication with patients with IDD, including the use of plain language, visual supports and responsive care.
- Identify person-centered approaches to care that promote patient engagement, shared decision-making, and respectful interactions with individuals with IDD in primary care

SECRET LEARNING OBJECTIVE

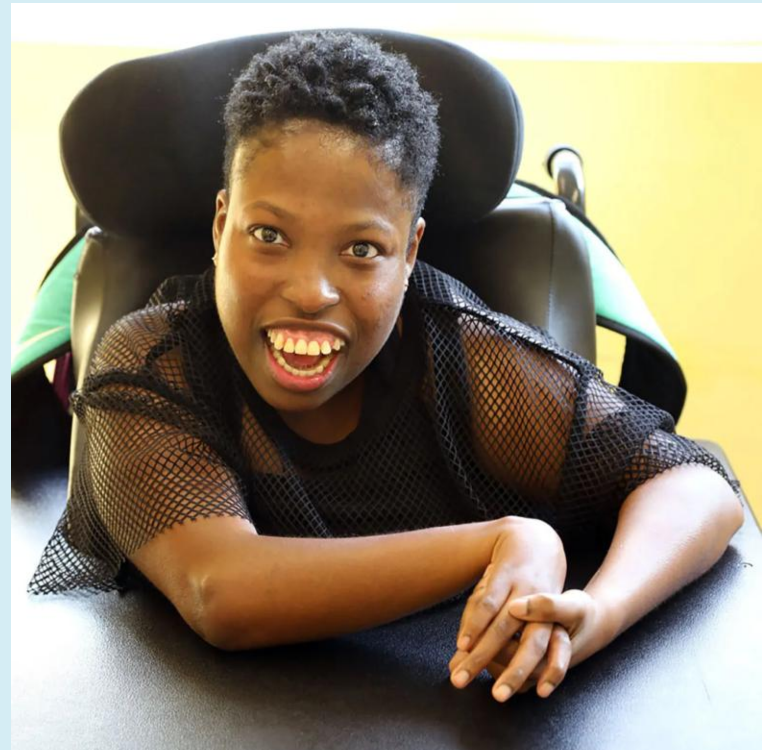
- For you to feel confident and inspired to welcome people with intellectual and developmental disabilities in your primary care practice.

PEOPLE WITH IDD

- Disability starting in childhood
- Expected to continue indefinitely
- Restricts functioning in several major life activities
  - Self-care
  - Receptive and expressive language
  - Learning
  - Mobility
  - Self-direction
  - Economic self-sufficiency
- Individuals with IDD

PEOPLE WITH IDD

- Have diagnoses of:
- Down syndrome/Trisomy 21
- Fetal Alcohol Syndrome
- Fragile X
- Autism
- Cerebral Palsy (CP)
- Intellectual Disability
- Epilepsy
- And many others



https://positiveexposure.org/album/cerebral-palsy/

PEOPLE WITH IDD

- Live and work in our communities
- Participate in our places of worship
- Want love and connection
- Provide love and support for others
- Want to live healthy, long lives
- Can learn new skills

INTELLECTUAL DISABILITIES

Level of Disability	% of People	Description
Mild	85%	Average mental age of around 9-12 years old. Disability may interfere with learning or complex tasks. With support, people can often work around these issues to live and work independently, though people often benefit from ongoing support, especially with complex tasks
Moderate	10%	Average mental age of around 6-9 years old. Communicate using simple language. People typically need some support for ADLs, work and medical appointments, money management
Severe	5%	Average mental age 3-6 years. Typically people communicate with simple gestures or words. Often need 24 hour support for ADLs.
Profound	<1 %	Average mental age under 3 years old. People typically communicate non-verbally. Benefit from 24 hour support for ADLs, basic care.

My.clevelandclinic.org/health/diseases/25015-intellectual-disability-id

LANGUAGE MATTERS

- Person-first language
- Person who uses a wheelchair vs. “wheelchair bound” or “confined to a wheelchair”
- Person with CP vs “afflicted by CP” or “victim of CP”
- Person with an intellectual disability vs “MR/DD”, “special person”

HEALTHCARE FOR PEOPLE WITH IDD

- Offices are often at least partly inaccessible
  - Exam tables
  - Scales
  - Clinician discomfort
  - Behavioral expectations

HEALTHCARE FOR PEOPLE WITH IDD

The New York Times

These Doctors Admit They Don't Want Patients With Disabilities

When granted anonymity in focus groups, physicians let their guards down and shared opinions consistent with experiences of many people with disabilities.

- Only 40% of physicians felt confident about their ability to provide the same quality of care to people with disabilities
- Only 56.5% of physicians strongly agreed that they welcome people with disability into their practices.
- Only 18.1% strongly agreed that the health care system often treats these patients unfairly.

Iezzoni LI, Rao SR, Ressalam J, Bolcic-Jankovic D, Agaronnik ND, Donelan K, Lagu T, Campbell EG. Physicians' Perceptions Of People With Disability And Their Health Care. Health Aff (Millwood). 2021 Feb;40(2):297-306. doi: 10.1377/hlthaff.2020.01452. PMID: 33523739; PMCID: PMC8722582

HEALTHCARE FOR PEOPLE WITH IDD

- People with IDD are more likely to have

- Low Income
- Obesity
- Diabetes
- High blood pressure
- Lower rates of cancer screening
- Earlier death

HEALTHCARE FOR PEOPLE WITH IDD

- Why?

- Access to Care
- History of adverse medical experiences
- Reliance on caregivers
- Communication challenges
- Clinician “Discomfort”

- So! Often not because of their disability, but because of the way our systems work (or don’t) for people with IDD

WHAT DO WE DO?

- Make a commitment: "People with IDD will get excellent primary care at my health center"
- Welcome people with IDD into our practices
- Improve accessibility of exam equipment
- Practice person-centered care
  - Behavior is communication!
- Learn communication strategies for individuals and supporters
- Understand baseline and the importance of changes from baseline
- Identify your patients with IDD
  - Likely UDS Table 6a measure for next year
  - Pulls from ICD-10 codes

HOW TO WELCOME PEOPLE WITH IDD

Ask about their needs and take steps to meet them

- "I bring a support person with me to help with my visit"
- "I get really anxious when I'm around a lot of people"
- "I use a wheelchair"
- "My son stims a lot in new situations"

- We are medical experts, but they are the experts on their abilities and experiences. When in doubt, ask!

ACCESSIBLE EQUIPMENT

ACCESSIBLE EQUIPMENT

UNDERSTAND BEHAVIOR

- Adverse event: An event that occurs that causes pain or fear, that you have no control over. Worse when you don't understand.
- Person-centered care
  - Shifting from- "that behavior is disruptive and unacceptable" to "what is that behavior communicating?" and "how can we help you feel safe?"
- Understanding baseline

COMMUNICATION CHALLENGES

- Ways to get the wrong idea:
  - Echolalia or automatic responses
  - Desire to please
  - Caregiver attending appointment doesn’t know patient well
  - Caregiver attending appointment and patient disagree
  - Diagnostic overshadowing
- When there’s no verbal communication
  - Understanding baseline
  - Behavior is communication
  - Simple things can get missed
- Role and responsibility of caregivers

COMMUNICATION CHALLENGES- STRATEGIES

- Open-ended questions
- Give more time
- Check for understanding
- Social stories
  - Blood Draw Social Story Final
- Teach-back
- Respect the information behavior provides
- Educate caregivers, ask for what you need
  - What to bring to appointments
  - Who can be reached for additional information
- Rely on other tools (physical exam, lab testing, imaging, time)

CASE #1

- A caregiver brings in Sarah, a 56 year old woman with a history of hypertension and moderate intellectual disability for a check up with primary care.
- Sarah doesn't communicate much verbally, but is smiling and gives you a high five when you hold up your hand. When you ask how she is she says "Great!"
- The caregiver reports that she noticed Sarah gagging herself with her hand last week. It happened a few times over a couple of days, then she stopped.
- The night staff had also reported she was waking up and crying out at night this week. She'd been able to fall back asleep and seemed fine in the morning, but this is a new behavior and she's disrupting others in the home. Can they have something for sleep?

CASE #1: YOUR THOUGHTS

- What questions do you have?
- What are you worried about?

CASE #1 CONCERNS

- Pain? Dental pain?
- When was her last bowel movement?
- Changes in staff?
- Med changes?
- Cough?
- Can we just give her something for sleep?

CASE #1

- Sarah’s vital signs were normal. Her exam is initially difficult, but you’re able to make her more comfortable and she allows you to examine her abdomen, heart, lungs and mouth. She seemed to be a little tender in her RUQ. No guarding.

PHYSICAL EXAM

- Physical Exam
  - Take a moment to ground yourself
  - Ask permission before touching, and give time for refusal
    - I’m going to use this light to look in your ears. Do you want to touch it? Now I’m going to touch your ear with it.
  - Demonstrate on yourself or another
    - I’m going to touch your neck now (while touching my own neck)
    - I’m going to listen to mom’s heart (do it), and now I will listen to your heart (approach)
  - Get permission to try again another time
    - It seems like you don’t want me to touch your neck now, can I listen to your heart then try again?
    - It seems like doing your pap smear is too hard for you today, thanks for trying, can we try again next visit?

CASE #1

- You order labs, and her AST, ALT and Alk Phos are all elevated.
- A RUQ u/s shows gallstones and a very enlarged gallbladder

LABS AND IMAGING

- Many people with IDD have a history of adverse healthcare experiences
  - Something painful or scary happening, you are powerless to stop it
- May see self-injurious or loud, agitated behavior
- Stay calm
- Safety first
- Ask patient and caregiver to prepare before testing
  - Calming strategies
  - Distraction strategies
  - Practice the story
- Build trust

CASE #1

- Sometimes you don't have a lot to go on.
- If there is a change from baseline, and it's not clear from the history and physical what is going on, you should keep looking.
- Hand-mouthing behavior is often a sign of GI issues. It should be investigated.

COMMUNICATION CHALLENGES

- Does my patient understand the treatment plan?
- Who is responsible for implementing the treatment plan?
- Who is the medical decision maker?

CASE #2

AH is a 47 year old with moderate intellectual disability, Down syndrome and type 2 diabetes who lives in a group home with 3 housemates. They have 24 hour care provided by a team of 8 staff members. At his most recent visit, the patient, caregiver and provider agreed on these goals:

1. See ophthalmologist
2. No more sugary drinks except on Friday movie night
3. Check blood sugar 2 hours after lunch every day

What might be some barriers to implementing these goals?

BARRIERS FROM CASE #2

- Does everyone understand the plan and why it's important?
- Staffing
- Transportation
- Who do we communicate with?
- Who needs to know to make this happen?
- Can the patient cooperate with an ophthalmology exam?
- Can the diet changes be enforced?
- Can the day program check his blood sugar? Do they need an order?

CARE OF CHRONIC CONDITIONS

- What makes this easier:
  - Many patients have support staff who provide and document medications.
  - Often home monitoring of weight, blood pressure, and blood sugar are possible.
  - Some people with autism or ID are really good at following rules

- What makes this harder:
  - Patient and caregiver education can take longer
  - Caregivers are often juggling multiple needs
  - Exercise can require creativity/support
  - Can be difficult to monitor labs

CARE OF CHRONIC CONDITIONS

- Leverage home monitoring abilities
- When setting goals, ask "who needs to know about this goal to make sure we can meet it?"
- Take agreement with a grain of salt, normalize change being difficult
- Be concrete about expectations for monitoring and goals (sometimes less flexible is better)
- If you have a program for high-risk case management, consider including patients like AH

UNDERSTANDING BASELINE BEHAVIOR

- Ambulation
- Communication
- Ability to perform ADLs
  - Hygiene
  - Cooking
  - Cleaning
  - Eating
  - Money management
- How do you show pain/discomfort?
- Sleep
- General behavior

- AWV documentation

SOME SPECIFIC BEHAVIORS

- Stimming– hand flapping, jumping, rocking, repetitive vocalizations
- Self-injurious behaviors- biting, head-banging, skin picking

- These can be baseline behaviors or changes from baseline. Ask!

CHANGES FROM BASELINE BEHAVIOR

- Not eating
- Not sleeping
- Hand mouthing
- Self-injurious behavior (hitting head, ears, biting self)
- Doesn’t want to go to program
- Calling out
- Doesn’t want to come out of her room
- “He just doesn’t seem right”

- Behavior is communication!

CHANGES FROM BASELINE

- Good history
- Medical evaluation- think delirium workup
  - Constipation, infection, blood sugar
- Social/environmental changes
- Sleep
- New medications

- People with IDD can and do have co-occurring mental illness, but…

EARLY DEATH

Adults with IDD die about 15-20 years earlier, on average, than adults without IDD and the causes are different:

- Constipation
- Aspiration
- Pneumonia
- Seizures
- GERD
- Dehydration
- Sepsis
- Skin breakdown

- Look for these things when patients have a change from baseline and think about prevention at all visits.

CONCLUSION

- People with intellectual and developmental disabilities have limited access to healthcare in our current system.
- Often people with intellectual and developmental disabilities have had adverse healthcare experiences.
- People with intellectual and developmental disabilities have poorer health outcomes for reasons that have nothing to do with their disability.

- Welcoming people with IDD into your practice and taking steps to support them can have a huge impact!
- You can do this!

CONCLUSION

- There are sometimes specific communication challenges when working with people with IDD
- You already have many skills that will help overcome those challenges and you've learned some new ones!

WHAT RESONATES WITH YOU

- Think about your practice, your patients, and the people I’ve described
- What ideas do you have about how you can be more welcoming to people with disabilities?
- What are you doing well?
- What support do you need?

REFERENCES

- IntellectAbility- https://replacingrisk.com/
  - 6 part series (paid) on caring for people with IDD

- Clinical Pearls in IDD Healthcare- by Craig Escude, MD

- Iezzoni LI, Rao SR, Ressalam J, Bolcic-Jankovic D, Agaronnik ND, Donelan K, Lagu T, Campbell EG. Physicians' Perceptions Of People With Disability And Their Health Care. Health Aff (Millwood). 2021 Feb;40(2):297-306. doi: 10.1377/hlthaff.2020.01452. PMID: 33523739; PMCID: PMC8722582
- My.clevelandclinic.org/health/diseases/25015-intellectual-disability-id
- https://positiveexposure.org

Please fill out our survey!

Find the survey link in the chat and at the close of the webinar.

Your feedback is very valuable and helps us to provide the CHCANYS network with relevant and engaging content.

COMMUNITY
HEALTH CARE
ASSOCIATION
of New York State

chcanys.org