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Best Practices Resource Guide for Health Centers serving Individuals with Developmental Disabilities

ACKNOWLEDGMENTS

Authors:

Jing Murray, MPH, Health Outreach Partners

Zi Wang, Health Outreach Partners

Special Thanks To:

On behalf of Health Outreach Partners, the authors would like to extend their gratitude and acknowledgment to the following partners:

Christina Arebalo and the team at the National Association of Community Health Centers (NACHC)

Kevin Luu, MPH(c), San Jose State University, Health Outreach Partners Graduate Intern

DISCLAIMER

This publication was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of awards as follow: U30CS16089 totaling $6,625,000 with 0 percent financed with non-governmental sources, 4 U30CS09743-18-01 totaling $847,285 with 0 percent financed with non-governmental sources. 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.

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INTRODUCTION

Building upon our work, in partnership with the National Association of Community Health Centers, this guide is intended to be used as a resource to strengthen communication and care strategies for individuals with Intellectual and Developmental Disabilities (IDD).

How to Use This Guide/Purpose:

Healthcare professionals who are IDD competent in their practice and care delivery are proven to positively influence the health outcomes of people with IDD.[1]

This *Best Practice Resource Guide* highlights communication strategies to help healthcare providers deliver care for patients with IDD that is effective, inclusive, respectful, and patient-centered and directed. People with (IDD) are patients first and are more alike than different from patients without disabilities. Like all patients, they have individual needs, preferences, abilities, and goals. Health care providers play a critical role in supporting their full participation in care through respectful, accessible, and person-centered communication.

While some individuals may choose or require support during health care visits, many make decisions independently—just like any other patient. This guide emphasizes patient-centered communication, presumed competence, and appropriate use of support.

This guide is intended for anyone working with patients with IDD in the health care and health delivery space.

By the end of this guide, you will...

- Walk away confident in providing care to patients with Intellectual and Developmental Disabilities
- Understand how health-related needs impact patients with Intellectual and Developmental Disability care and access to healthcare
- Explore practical strategies and communication techniques both at the individual and health center level to support patients with Intellectual and Developmental Disabilities

GETTING STARTED

What is Intellectual Disability?

The Centers for Disease Control and Prevention (CDC) defines intellectual disability as "limits to a person's ability to learn an expected level and function of daily life...Intellectual disability can be caused by a problem that starts any time before a child turns 18 years old – even before birth. It can be caused by injury, disease, or a problem in the brain".[2] Intellectual disability is the most common developmental disability affecting intellectual functioning and adaptive behavior.[4]

Diagnoses of intellectual disability include Down syndrome, Fragile X syndrome, fetal alcohol syndrome, and Prader-Willi Syndrome.[2]

While intellectual disability causes limitations on a person's mental and cognitive abilities, the effects can vary widely, resulting in a range of limitations on intelligence, learning, and everyday life skills.

A common misconception is that intellectual disabilities only limit intelligence when they are assessed by an Intelligence Quotient (IQ) test. An IQ test is only one piece of information in the diagnoses process, and increased research is emerging that it is an antiquated marker.[5] While an IQ test is a necessary piece for the IDD diagnosis, it is not the only marker that determines the severity of the disability. For example, people can have an average or above average IQ but may not be able to complete other abilities and tasks necessary for everyday life. Other people can have "lower-than-average" IQ but can execute daily tasks of living strongly enough that they don't meet the criteria for intellectual disability, or they have a milder form of intellectual disability than the IQ test suggests.[5]

What is Developmental Disability?

The CDC defines developmental disability as a "group of conditions due to an impairment in physical, learning, language, or behavior areas".[3] These conditions begin during a child's developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime. Most developmental disabilities begin before a baby is born, but some can happen after birth because of injury, infection, or other factors.

Examples of diagnoses of developmental disabilities are: Cerebral Palsy, Tourette syndrome, Autism Spectrum Disorder, and Epilepsy.[4]

What is Intellectual and Developmental Disability (IDD)?

Intellectual and Developmental Disability, commonly known as IDD, refers to situations when both Intellectual and Developmental Disabilities are present.[4] The term encompasses life-long challenges, including intellectual disabilities, physical disabilities or both. Physical and cognitive disabilities can and do often co-occur in people with IDD.

It is important to note that you can have a developmental disability such as cerebral palsy and have other co-occurring disorders that are not intellectual disabilities.

IDD and Health Outcomes Landscape:

As a patient population, people with IDD have worse health outcomes than people without disabilities. Gaps in health outcomes people with IDD face are:

- Physical Health
- Mental and Behavioral Health
- Sexual and Gynecologic Health
- Health Care Access, Quality, and Education

Physical Health:

People with IDD often have additional co-morbidities. One of the most common co-morbidities across all types of IDD is epilepsy and other seizure disorders. People with IDD are more likely to have cardiovascular disease, hypertension, arthritis, osteoporosis, type 2 diabetes, asthma, and obesity.[1]

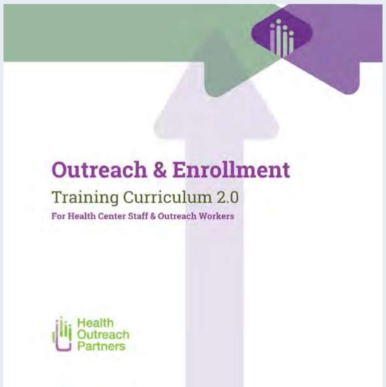
Mental and Behavioral Health:

It is estimated that 40% of people with IDD have a mental or behavioral disability. People with IDD are commonly diagnosed or characterized with “challenging” behavior. This characterization of “challenging” is a subjective characterization that is often rooted in a maladaptive behavior that can cause harm to the person with IDD or others around them. Considering the person’s environmental factors and Health Related Needs screenings are important to understanding your patient with IDD. This population is often prescribed psychotropic medications without official mental health diagnoses. They also experience high rates of institutionalization.[1]

Sexual and Gynecologic Health and Identity:

There is a prevalent myth that people with IDD are not interested in or capable of intimate relationships. This means that people with IDD often receive little to no sex education and do not often receive frequent or adequate gynecological health care. There is increasing demand from people with IDD for comprehensive sexual and gynecological health education and resources so they can make informed choices and express themselves with dignity.[1]

Outreach and Enrollment, Ensuring that patients with IDD are able to enroll in and access public health insurance programs is imperative for this population. Health Outreach Partners’ Outreach and Enrollment 2.0 Curriculum offers strategies for patient support services (such as community health workers) to maximize their outreach strategies with the resources they have.



Outreach & Enrollment
Training Curriculum 2.0
For Health Center Staff & Outreach Workers

Health Outreach Partners

Health Care Access, Quality, and Education:

It is estimated that 8 million people across the United States have an intellectual or developmental disability. This number is most likely underreported, as some estimates calculate there are anywhere from 8 to 16 million people who have an intellectual or developmental disability.[6]

Oftentimes, people with IDD have unmet health needs due to gaps and barriers in access to health services. While the Americans with Disabilities Act (ADA) lawfully requires accessibility and accommodations in health care settings, 72% of adults with disabilities frequently report not receiving accommodations.[1]

The exact number is unknown, but it is estimated that 50% of people with IDD experience poverty.[1] The majority of non-elderly people who have an IDD use Medicaid to access health services. In an estimate from 2019, 1.6 million adults with IDD used some type of Medicare or Medicaid program to access health services.[1] 8 of 10 non-elderly Medicaid enrollees with IDD are children under 19 years of age, making Medicaid a vital recourse to access health services.[6] Medicaid enrollees with IDD ages 19-64 spend an estimated $50,000 a year on medical expenses. The average Medicaid enrollee who does not have IDD spends roughly $6,000 a year on medical expenses.[6]

BEST PRACTICES

Provider Communication Strategies: What Providers Can Do

Core Communication Principles

1. SPEAK DIRECTLY TO THE PATIENT

- Always address the patient first and speak directly to them, not to their support person.[7]
- Ask the patient whether and how they would like their support person involved during the visit.
- Maintain eye contact with the patient and use appropriate, respectful body language.
- Treat the patient as you would any other adult patient.
- Move at a comfortable pace; check for comprehension before transitioning between topics.
- Repeat or reword information as needed to support understanding.
- Use clear, plain language and avoid unnecessary medical jargon.
- Allow additional time for the patient to process information and respond.
- Ask open-ended questions and confirm understanding, when appropriate, by asking the patient to explain information back in their own words.

Additional Considerations for Patients on the Autism Spectrum

Some patients on the autism spectrum may experience sensory sensitivities to light, sound, touch, or textures, and may prefer limited eye contact. These sensitivities can affect how patients experience clinical environments and medical exams. Health centers and providers can support patient comfort and engagement by making small adjustments to care delivery.[8,9]

Health centers and providers can support patients by:

- **Explaining each step of the visit or exam before it occurs**, especially before any physical contact or procedures.
- **Asking about sensory preferences** (e.g., lighting, noise level, touch) and adjusting the environment when possible.
- **Allowing flexibility with eye contact**, recognizing that some patients may communicate more comfortably without direct eye contact.
- **Reducing sensory stimuli, when possible**, such as dimming lights, lowering noise levels, or minimizing background interruptions.
- **Allowing additional time** for the patient to process information and respond.
- **Providing clear, step-by-step instructions** and checking for understanding.
- **Offering breaks during longer appointments or exams** if the patient becomes overwhelmed.
- **Asking the patient how they prefer to be supported**, including whether they would like a support person involved.

Small environmental adjustments and clear communication can help reduce sensory stress and create a more accessible and respectful health care experience.[8,9]

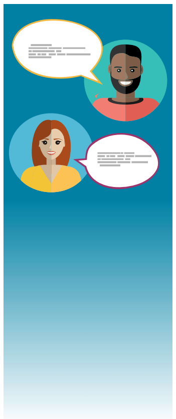
KEY REMINDER:
When a support person is present, their role is typically to assist the patient—not to replace the patient's voice

2. HONOR PATIENT AUTONOMY

- Always presume competence unless it is clearly demonstrated otherwise.
- If a patient has a speech difference or communication impairment, it is appropriate to respectfully ask the patient to repeat themselves if needed.
- Do not ask the support person to interpret or repeat what the patient said without first obtaining the patient's permission.
- Do not default to the support person when discussing care plans, decisions, or consent.
- Ask the patient how they would like to be supported during the visit.
- Obtain the patient's permission before any examination, procedure, or physical contact.
- Respect the patient's preferences, choices, and decision-making role.

KEY REMINDER:
Patients with IDD have the same autonomy as any other patient and should be supported to exercise it in ways that reflect their preferences and abilities. Healthcare providers should ask patients how they wish to participate in health care decisions.[10,11]

Scenario-Based Example



Scenario:

Mary has cerebral palsy (CP) and uses a wheelchair. She arrives at her appointment accompanied by a support person.

When the health care provider enters the exam room, they greet Mary directly and also acknowledge the support person. The provider asks Mary, "How would you like to be supported today?"

Mary explains that her support person is present only to assist with transferring from her wheelchair to the exam table. She states that she will communicate directly with the provider and make all medical decisions herself.

The provider honors Mary's preferences by speaking directly to her throughout the visit and involving the support person only as requested.

Acknowledging Provider Challenges

Health care providers may encounter communication challenges when working with patients who have cognitive differences, communication barriers, or behaviors shaped by prior negative health care experiences. These challenges are real and valid; however, they do not diminish a patient's right to respect, dignity, and equitable care.

Providers are encouraged to:

- Approach each patient with patience and openness
- Seek clarification rather than making assumptions
- Use accommodations, communication aids, or additional supports when needed
- Seek out more training for providing care for patients with IDD.
- Treat each patient with respect, dignity and attention, while recognizing that each patient is an individual and not every patient is the same.
- Recognize when they do not know something and seek clarification before making a decision.
- Advocate for their patients when they notice other providers not providing patient-centered care or making assumptions based on bias rather than facts.

KEY TAKEAWAY:

Effective communication is essential to inclusive health care delivery. By speaking directly to patients with IDD, honoring their autonomy, and recognizing individual preferences and support needs, providers can create a more inclusive, respectful, and effective health care experience for all patients.[12]

Motivational Interviewing

Providers can employ Motivational Interviewing (MI) as a best practice when serving patients who have an intellectual or developmental disability. Motivational Interviewing is an evidence-based approach that blends a variety of foundational approaches from cognitive and social psychologies.

MI is a person-centered goal-oriented practice that inherently recognizes the patient's autonomy and competence. It infuses acceptance and empathy as a necessary condition in relating and relaying health information and education.[13]

Motivational Interviewing can be thought of as a four-bucket process. It should be noted that the following processes do not have to follow each other in numerical order. This process is most successful when the provider can recognize and identify what the patient has already accomplished and where would be the most useful place to start along the Motivational Interviewing continuum.

The process of Motivational Interviewing:

RELATIONSHIP BUILDING (ENGAGING)

This is all about building trust with your patient. Creating and establishing a non-judgmental understanding of the patients' disability, understanding how it impacts daily life, and making sure you are talking to the patient and not their support person.

FINDING A DIRECTION (FOCUSING)

This bucket focuses on establishing your patient's priorities. Ensure that you are an engaged listener and that you are not rushing the patient. Give them ample time to process and gather their thoughts, and have alternative communication methods available if they are non-verbal. The key element in this bucket is identifying the patient's health concerns and goals.

GOAL ORIENTATION (EVOKING)

This bucket is focused on understanding your patient's disability, and how it impacts their daily life. It requires digging into how social risk factors such as housing, food, and employment, can and do impact their ability to address their health issues and how they affect their health outcomes.

TRANSLATING MOTIVATION INTO ACTION (PLANNING)

This bucket is action oriented. Health care providers who are using MI with their patients with IDD can use the following questions to guide their action steps with their patients:

- What care coordination does the patient need next?
- What existing supports can this patient leverage to be successful?
- What existing partnerships does my clinic have to support the referral process?
- How can I ensure the information gathered in today’s appointment follows in the patient’s care continuum?

Health Center Improvement

IMPLEMENTING HEALTH-RELATED NEEDS SCREENING

Routine implementation of Health-Related Needs screenings is one key organizational action health centers can take to advance inclusive, patient-directed care. Conducting a Health-Related Needs screening before or during medical appointments enables health centers to systematically identify non-medical factors that may affect access to care, visit participation, and health outcomes.

Health-Related Needs are the non-clinical factors that impact health outcomes, including the conditions in which people are born, grow, work, live, and play.[14] For people living with IDD, these factors often compound existing barriers, contributing to more severe health outcomes and creating additional challenges in care delivery compared to the general population. Integrating disability awareness into care delivery is essential to increase understanding, build trust, and motivate individuals with IDD to engage proactively in their own health care. In this context, embedding Health-Related Needs screening into standard workflows is a critical step toward inclusive, patient-centered care. Implementing Health-Related Needs screenings as an organizational action also shifts responsibility from individual providers to the organization itself, enabling consistent, proactive, and inclusive responses across Health Centers. It increases awareness, builds motivation, and supports proactive engagement in care.

Purpose

Routine Health-Related Needs screening for patients with IDD supports health centers in:

- Identifying social needs that impact access, engagement, and outcomes
- Informing visit planning and care coordination
- Facilitating timely referrals to internal services and community-based resources
- Reducing missed appointments and delays in care
- Advancing continuous quality improvement and health outcome goals

Implementation Considerations

Health centers may conduct Health-Related Needs screenings at multiple points in the care process, including:

- Appointment scheduling or registration
- Pre-visit planning or intake
- Rooming or early in the clinical encounter
- Routine intervals or when patient circumstances change

When feasible, completing screening prior to the visit allows care teams to anticipate needs and coordinate supports in advance.

Recommended Screening Tools

Health centers should select screening tools that align with workflows, patient populations, and quality improvement priorities. Tools referenced in this best practice guide include:

PRAPARE: Protocol for Responding to & Assessing Patients' Assets, Risks and Experience

PRAPARE strengthens the relationship between patients and care team members by supporting shared decision-making, priority setting, and immediate care improvements based on identified needs. At the organizational level, it enables targeted interventions, improves use of patient support services, supports cross-sector partnerships, enhances risk stratification, and drives quality improvement efforts.

ACH: Accountable Health Communities Tools

The ACH screening tools provide a standardized approach to identifying core social needs such as housing, food, and transportation. They support consistent data collection across settings, enabling health centers to connect patients to resources efficiently while also informing community health strategies and system-level improvements.

IntellectAbility's Health Risk Screening Tool

This tool is designed specifically for individuals with IDD, helping identify health and safety risks that may otherwise be overlooked. It supports more tailored care planning and can improve clinical decision-making by highlighting both medical and social factors unique to this population.

Screening should be conducted using plain language, accessible formats, and patient-preferred supports.

Scenario: Health Related Needs Screening in Practice

Scenario:

Alex is a person with Autism Spectrum Disorder. During appointment scheduling, a health center administers a Health-Related Needs screening tool in a format that is most accessible for Alex. The screening identifies that Alex has some transportation challenges.

Prior to the appointment, staff arranges transportation support and notifies the care team. As a result, Alex arrives on time, the visit proceeds as scheduled, and care decisions are not delayed.

KEY TAKEAWAY:

Routine Health-Related Needs screenings are a foundational, systems-level strategy that enables health centers to identify barriers early, coordinate supports, and deliver inclusive care for patients with IDD.

Transporation

Transportation has often been an identified barrier in people's ability to access healthcare. When intersected with disability, transportation significantly impacts health outcomes. People with an intellectual or developmental disability are less likely to drive, thus having fewer transportation options available to them. Many people with IDD use public transportation, but most public transportation systems are not accessible to people with IDD. A person with IDD's ability to navigate and access public transportation can be complicated by a variety of factors including broken elevators, lack of sidewalks, inaccessible routes, living in rural areas, or living in hyper urban areas where sidewalks or bike lanes are incredibly congested.[15,16]

One study found that amongst 3,000 people who have an intellectual or developmental disability, those that had access to reliable transportation that could accommodate them were more likely to have their basic needs met.[15]

It is imperative for health centers to address transportation barriers for all of their patients, but especially for their patients with IDD. Transportation is proven to positively impact a person with IDD's overall health, safety, community integration, and social well-being.

Health Outreach Partners has long been a leader in providing training and technical assistance webinars and curriculums for health centers to identify and address transpiration barriers their patients may face. If you are seeking transportation resources check out HOP's [Transportation Quality Improvement Toolkit 2.0]()

Transportation & Health Access

a quality improvement toolkit 2.0

Using a Continuous Quality Improvement Process to Reduce Missed Appointments Due to Transport Barriers

WHAT’S NEXT/TAKE ACTION

What's Next/Take Action

To conclude, patients with IDD have the same right to participate in the management of their health and healthcare as a person without a disability. Below is a list of individual and organizational actions you can take to begin working towards closing the gaps in health outcomes amongst people with IDD.

Individual:

- Speak to the patient and not their support person
- Use principles of Motivational Interviewing when interacting with people with IDD
- Give priority to the person's determination of their own disability-related needs and what sort of assistance or accommodation will meet those needs.

Organizational:

- Expand training opportunities for healthcare staff about people with IDD
    - Healthcare staff, health center staff, health professionals are undertrained in caring for patients with IDD. Expanding opportunities for staff to build capacity in care delivery to patients with IDD is key.[17]
- Form or identify partnerships in your area that can strengthen your health center's referral structure or continuums of care.
- When onboarding new providers, include training about delivering care for people with IDD.
- Conduct the Health Center Readiness Assessment from HOP's Transportation Quality Improvement (QI) Toolkit 2.0 to see where your health center lands amongst readiness.

Resource Guide Takeaway

REAL WORLD CONSEQUENCE

Zi Wang's Point of View

As a person living with multiple disabilities, including IDD, I have experienced a range of barriers when accessing health care. Transportation challenges have made it difficult at times to attend appointments consistently; there have been instances where I canceled appointments because I did not have the physical or mental capacity to figure out how to get to and from the clinic. Accessibility within clinical settings can also vary widely. I often need to call ahead and be very specific about the accommodations I need, which can be exhausting.

More often than not, when I attend appointments with a support person, healthcare staff and providers direct questions to the support person instead of speaking to me directly, speaking about me in the third person while I am in the room, which can feel dismissive, limiting, and even infuriating. I often have to ask providers and clinic staff to speak to me directly, and even then, some are unwilling to adjust. In many cases, providers enter the room without awareness of my disabilities or the accommodations I need. My experience reflects the broader challenges that people with disabilities face when accessing health care.

This guide helps bridge that gap by supporting both providers and health systems in better understanding the real-world challenges patients with IDD may face when receiving care. It aims to reduce the need for patients to repeatedly advocate for themselves by equipping health centers with clear guidance on what to do. The guide emphasizes that inclusive care does not require entirely different treatment, but rather thoughtful, patient-centered approaches that ensure inclusion and respect. It offers practical, actionable strategies, such as improving communication practices and implementing Health Related Needs screening to address common barriers. Importantly, it also acknowledges the challenges providers may face, encouraging a supportive approach to improvement rather than placing blame. In doing so, it aims to strengthen partnerships between patients and providers and improve the overall quality of care for individuals with IDD. This guide, when used by health centers, will make a real difference for patients with disabilities like me.

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