

Partners in Health: Inclusive Healthcare Appointments for People with Intellectual and Developmental Disabilities

Self Advocates: Anna Attla, Logan
Turner, Travis Sherrer

Parent/guardian: Cheri Scott

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Learning Objectives

- Describe prevalence of disabilities in adults and children, health disparities and barriers that people with intellectual and developmental disabilities (I/DD) encounter
- Understand effective and ineffective approaches by listening to stories from individuals with lived experience
- Review strategies to improve communication with patients and parents/guardians
- Identify resources and further learning opportunities

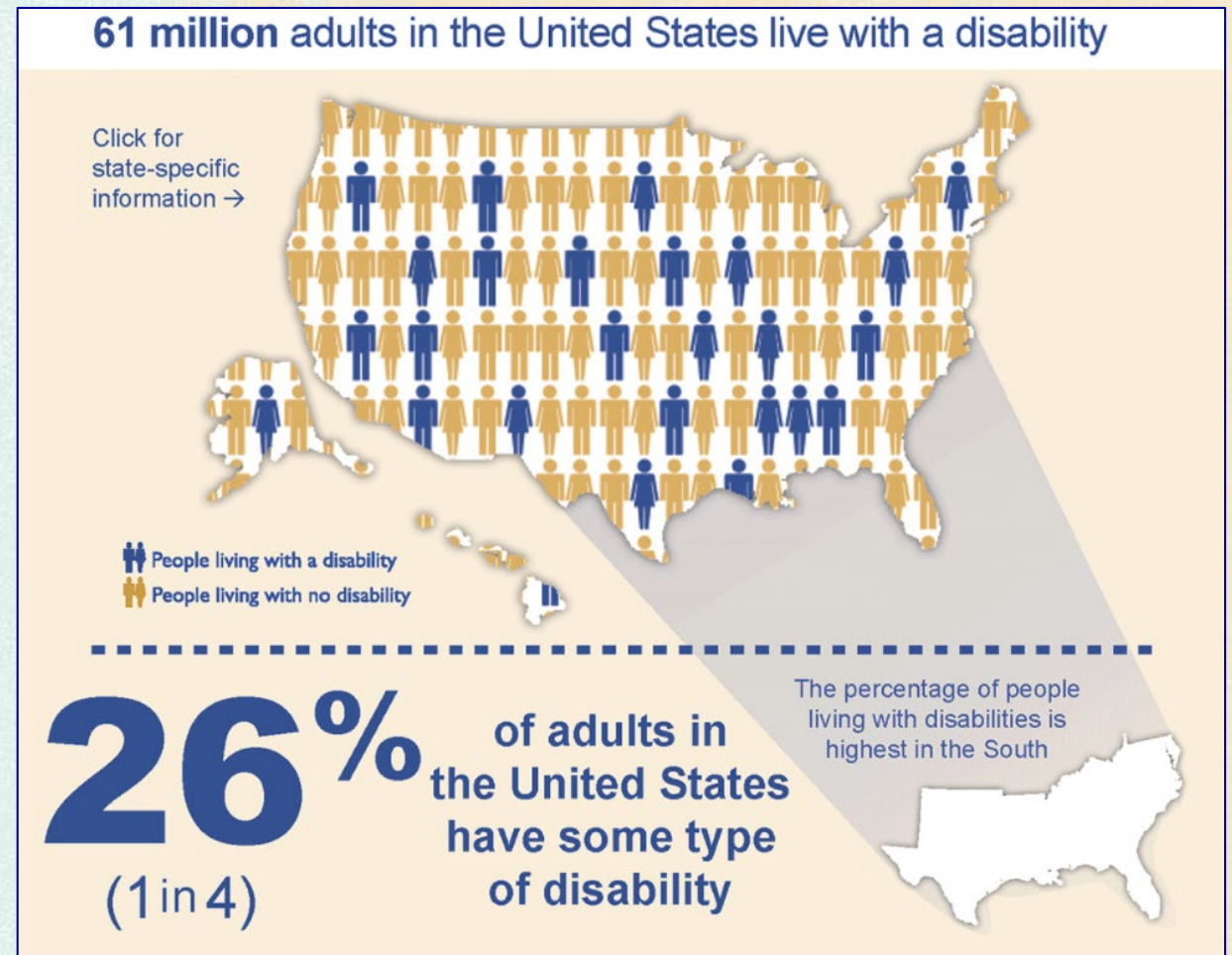
Prevalence of Disabilities in the United States

Prevalence – Children

- Percentage of children with disability in the United States increased
 - From 3.9% in 2008 to 4.3% in 2019
 - Over 3 million children
- Most common type of disability in children is cognitive difficulty
(Young, 2021)
- Children living in rural areas more likely to be diagnosed with developmental disability
 - Significantly less likely than those in urban areas to have seen mental health professional, therapist, or had well-child checkup in the past year
(Zablotsky & Black 2020)

Prevalence – Adults

- 61 million adults in the U.S. have a disability
- This is 26% of the adult population
- As a healthcare provider, you should expect to work with people who experience disabilities

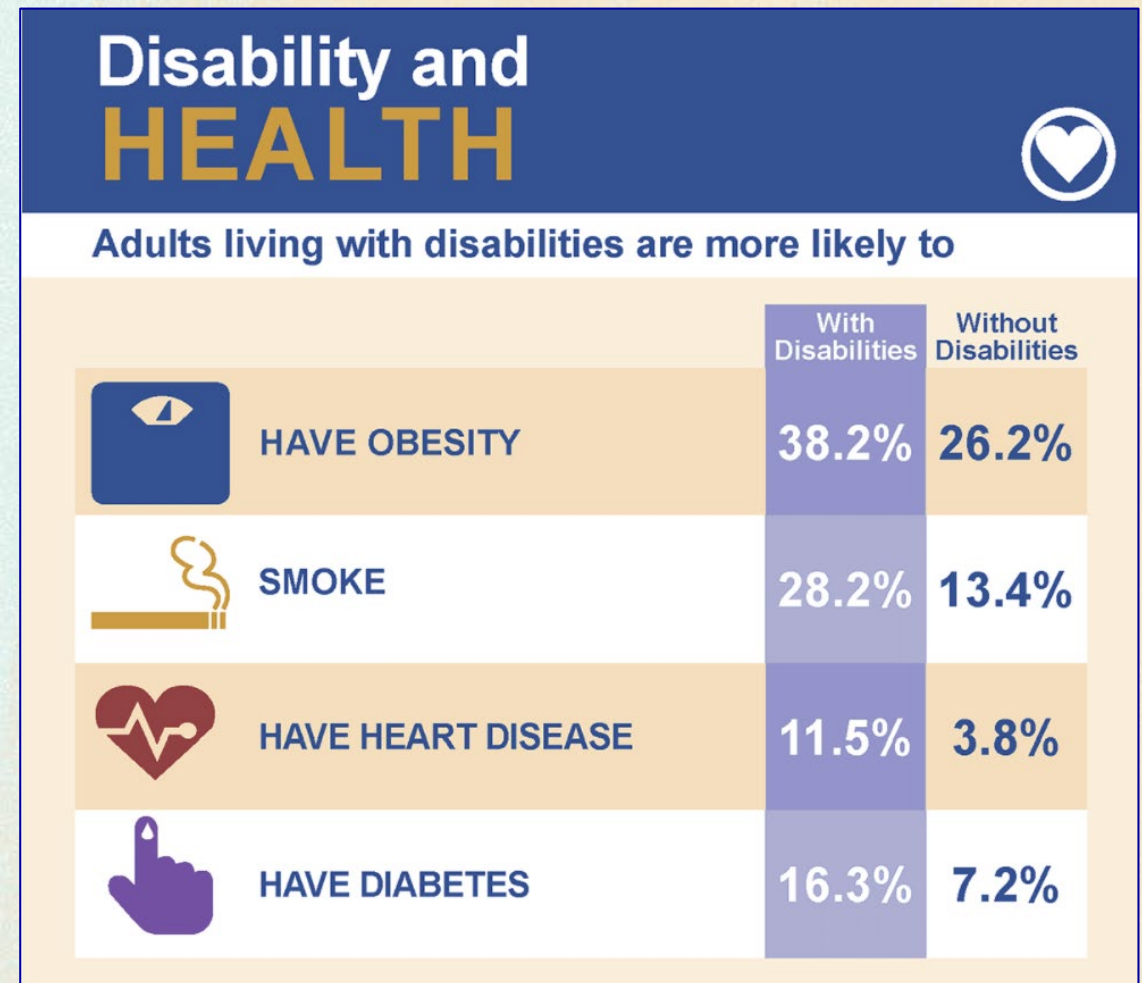


Health Disparities and Increased Need for Healthcare Access

Increased Need for Health Care Access

- People with disabilities often experience more health challenges than people without disabilities
- In Alaska, people with disabilities more likely to:
 - Have high blood pressure
 - Be inactive
 - Smoke
 - Experience obesity

National Data



“Disability Impacts All of Us”

Need for Mental Health Support

- Adults with disabilities report frequent mental distress almost **5 times** as often as adults without disabilities
- Important to ask about mental health during appointments and refer to services



“The Mental Health of People with Disabilities”

Impact of COVID-19 on People with Disabilities

- Review of 64,858,460 patients across 547 health care organizations
- Having an intellectual disability was strongest risk factor for presenting with Covid-19
- Other than age, having a disability was the strongest risk factor for dying from Covid-19

(Gleason, Ross, Fossi, Blonsky, Tobias, & Stephens, 2021)

Potential Barriers to Healthcare for People with I/DD

Common Barriers

- Healthcare providers may assume patients with I/DD are unable or limited in patient participation during healthcare visits
- Inadequate training of healthcare staff on how to best support/include people with I/DD
- Insufficient visit time
- Inability to communicate effectively with healthcare staff regarding their needs

Healthcare Provider Perceptions

- Recent study entitled “Physicians’ Perceptions of People with Disability and Their Health Care” published in Health Affairs, Feb. 2021
- Survey of 714 practicing US physicians
- 82% reported that people with significant disability have worse quality of life than non-disabled people
- 41% were very confident about their ability to provide the same quality of care to patients with disabilities as those without
- 57% strongly agreed that they welcomed patients with disabilities into their practices
- Room for improvement to ensure equal access and quality

Learning from Self-Advocate and Parent/Guardian Experiences

Self-Advocate Experiences

- **Anna**
 - Effective communication from long-term provider
 - Recommendations for building relationship with new providers
- **Logan**
 - Experience with providers following injury
 - Re-thinking the pain scale
 - Guardian, parent, support person role
- **Travis**
 - Providers who communicated well
 - Providers who need to explain what they are doing more effectively



Parent Experience

- **Cheri**
 - Speak to the patient first
 - Need for de-sensitization prior to and during appointment
 - Expect multiple appointments to achieve full exam
 - Communication
 - Give patient time to answer
 - Use communication aids if needed

Communication Strategies

Self-Advocate Recommendations

- Build on strengths, abilities, and interests
 - Really listen and talk with the person
 - Get to know them and what they value
 - Don't assume things about who they are or what they understand

Actions You Can Take

- ✓ **Speak directly to the patient.**
 - ✗ Don't avoid contact or speak only to the support person in the room.
- ✓ **Speak normally. Treat adults like adults. Be respectful.**
 - ✗ Don't speak louder or use an exaggerated tone unless needed by the patient.
- ✓ **Respect and use patient's communication system.**
 - ✗ Don't give up if the patient has difficulty with verbal communication.
- ✓ **Watch for signs of confusion or comprehension. Provide clarification, when needed.**
 - ✗ Don't ignore signs of confusion, fear, and anxiety.
- ✓ **Make language visible. Use gestures, pictures, and objects in the room to support what you are saying.**
- ✓ **Repeat important ideas different ways.**
 - ✗ Don't use only medical terminology to explain concepts.
- ✓ **Explain one concept at a time.**

Practical Skills Demonstration

- Video for healthcare providers focused on building skills to communicate effectively with patients with I/DD
- Includes:
 - Recommendations from self-advocates
 - Demonstrations by physicians working with patients



Communication Tips for
Healthcare Providers
with Patients Who Experience
Intellectual/Developmental Disabilities
(I/DD)

<https://www.youtube.com/watch?v=OKyZcui0dqc>

Tools and Resources You Can Use To Provide More Inclusive Healthcare Experiences

Society of Developmental & Behavioral Pediatrics

- Dedicated to improving developmental and behavioral health of children
- Promotes research, education, advocacy, and practice
- Advocates for integrated approach to biological, psychological, social, educational, and cultural influences
- Professional resources, journal links, calendar of updated training opportunities
- <https://sdbp.org/>



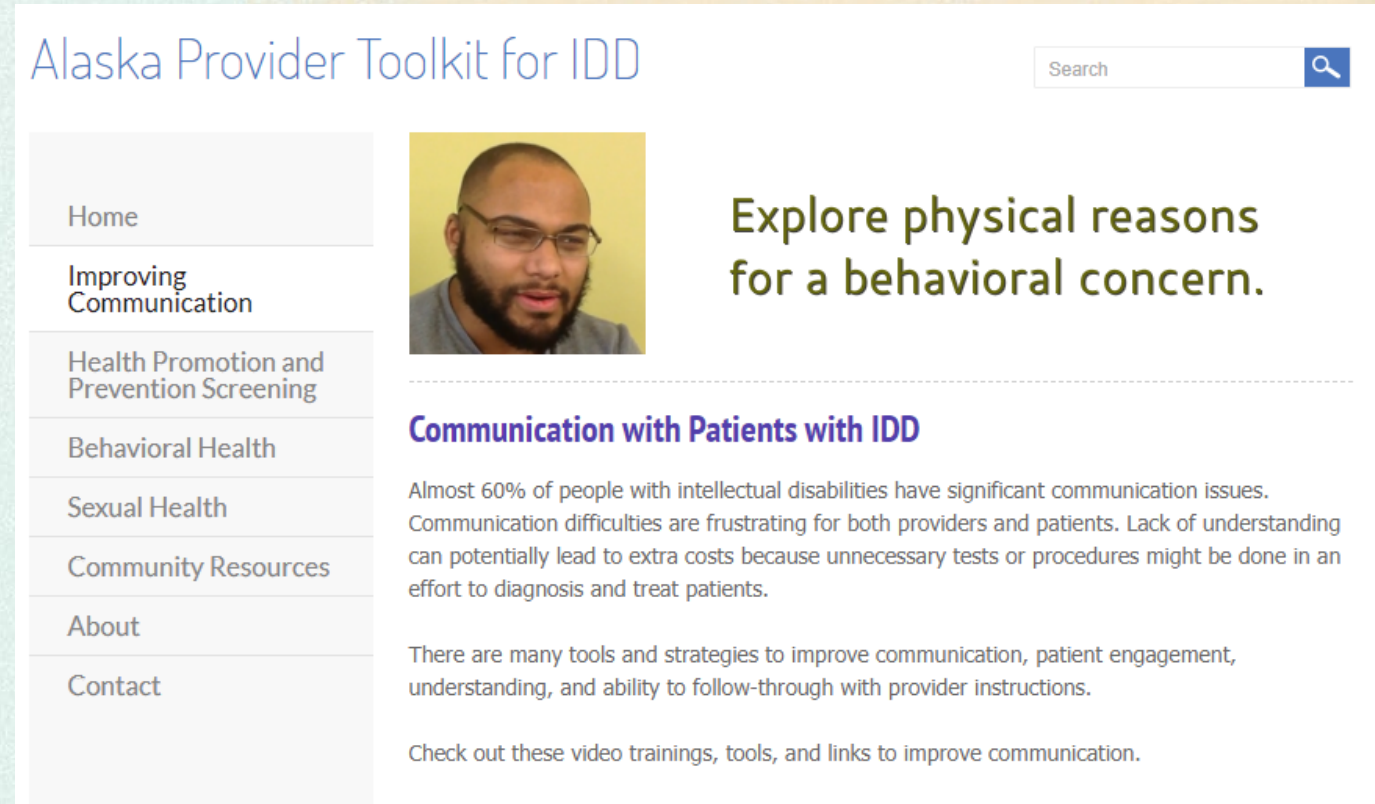
Interprofessional Leadership for Developmental-Behavioral Health

American Association of Developmental Medicine and Dentistry (AADMD)

- Committed to improving the quality of healthcare for people with intellectual and developmental disabilities
- Annual conference, monthly webinars: Virtual Grand Rounds
- Includes practical toolkits and resources for healthcare providers
- AADMD: <https://www.aadmd.org/>
- Webinar Series: <https://aadmdconference.com/webinars>
- UAA Chapter of AADMD:
<https://uaa.campuslabs.com/engage/organization/aadmd>

Alaska Provider Toolkit

- Resources online hosted by UAA, Center for Human Development
- Includes video learning opportunities, links, and tools
- <https://providertoolkitak.webly.com/>



Alaska Provider Toolkit for IDD

Search

Home

Improving Communication

Health Promotion and Prevention Screening


Behavioral Health

Sexual Health

Community Resources

About

Contact



Explore physical reasons for a behavioral concern.

Communication with Patients with IDD

Almost 60% of people with intellectual disabilities have significant communication issues. Communication difficulties are frustrating for both providers and patients. Lack of understanding can potentially lead to extra costs because unnecessary tests or procedures might be done in an effort to diagnosis and treat patients.

There are many tools and strategies to improve communication, patient engagement, understanding, and ability to follow-through with provider instructions.

Check out these video trainings, tools, and links to improve communication.

Alaska ECHO



- Virtual learning community
- Allows people across the state to learn from specialists
 - Specialists learn from participants
- Current ECHO projects include: Public Health Science, Behavioral Interventions for Early Childhood, Head Injury for Medical Providers, Neurodevelopmental Disabilities, Pain & Opioid Management
- Register for ECHO projects that interest you:
<https://www.uaa.alaska.edu/academics/college-of-health/departments/center-for-human-development/AK-ECHO/index.cshtml>

Contact Information

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