# PADDC Module 1

Module 1: Communication, Common Sense, and Nuance: Care of Patients with Intellectual and Developmental Disabilities (IDD)

Lesson 1: Social determinants of health

Lesson 2: Racial and ethnic differences

Lesson 3: Health disparities faced by patients with IDD

Knowledge check and Section 2 conclusion

SECTION 3: CARING FOR PATIENTS WITH IDD

Lesson 1: Underlying beliefs and ableism

Lesson 2: Disparities related to diagnostic overshadowing

Lesson 3: The transition from pediatric to adult care for individuals with IDD

Lesson 4: Communication as a primary tool

Lesson 5: Building rapport

Lesson 6: Supportive tools for visits

Knowledge check and Section 3 conclusion

CONCLUSION

Conclusion of Module 1

# Introduction

This project is funded by the Pennsylvania Developmental Disabilities Council (PADDC). Dr. Mary Stephens and Karin Roseman from the Jefferson FAB (For Adolescents and Beyond) Center for Complex Care were recipients of a grant from PADDC to fund their project: **Increasing Access to Quality Healthcare for People with Disabilities: A Co-Designed Educational Curriculum for Family Medicine Residents.** Please contact Rosemary Corcoran (ryc244@jefferson.edu) with any questions about this project.


Thomas Jefferson University


Pennsylvania Developmental Disabilities Council

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This module serves to provide information on the care of people with disabilities. Interactive knowledge checks are included throughout the module to allow for reflection, understanding of materials, and provide opportunity for self-assessment. Further discussion related to course topics can be found on an interactive discussion board linked here, and at the conclusion of this module.

By the end of this course module, learners should be able to:

- Discuss barriers and pitfalls for youth with intellectual and developmental disabilities (IDD) transitioning from pediatric to adult care

- Apply strategies for involving individuals with IDD in achieving their healthcare goals and maximizing their

outcomes

- Discuss decision making in advance of the 18th birthday for all patients with IDD
- Identify practical strategies to consider for office visits

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**If you are a healthcare professional or a student in training to be a healthcare professional, there is a pre-assessment to complete before continuing through the Learning Module.**

**If you are not a healthcare professional or student, please answer the screener question, then you may move straight into the Learning Module.**

Are you a healthcare professional or a student in training to become a healthcare professional?

Please type "yes" in the box below to acknowledge that you have completed the pre-assessment above before moving forward.

Type your answer here

SUBMIT

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What is one thing you are hoping to learn from this module, or future

**Note: If you do not complete all of the learning material at one time and would like to pause and return at a later time, you may do so. The system will not save your progress. Make a note of where you stopped and you may return at any point.**

CONTINUE

# Lesson 1: Medical education and disability

Investigate the following flashcards to learn about disability education trends in medical education. Guess or write down your answer, then *click to turn the flash card* over to see the true statistic. [1]

What percentage of residents do you think receive disability education during medical school?

Answer: 34.6%

What percentage of residents do you think receive disability education during residency?

Answer: 11.2%

Guess what percentage of residents expressed interest in further education on the topic of disability education.

Answer: 96%

Is disability education a mandatory part of medical school curriculum?

Answer: No

**Want to learn more?**

A survey of internal and family medicine residents: Assessment of disability-specific education and knowledge [1]

Disability education is not a mandated part of medical student curriculum. Only a small percentage of students have received disability-specific education.

READ MORE

## Stop & Reflect

Did you receive disability education during your training as a provider?

How might this inform your daily practice?

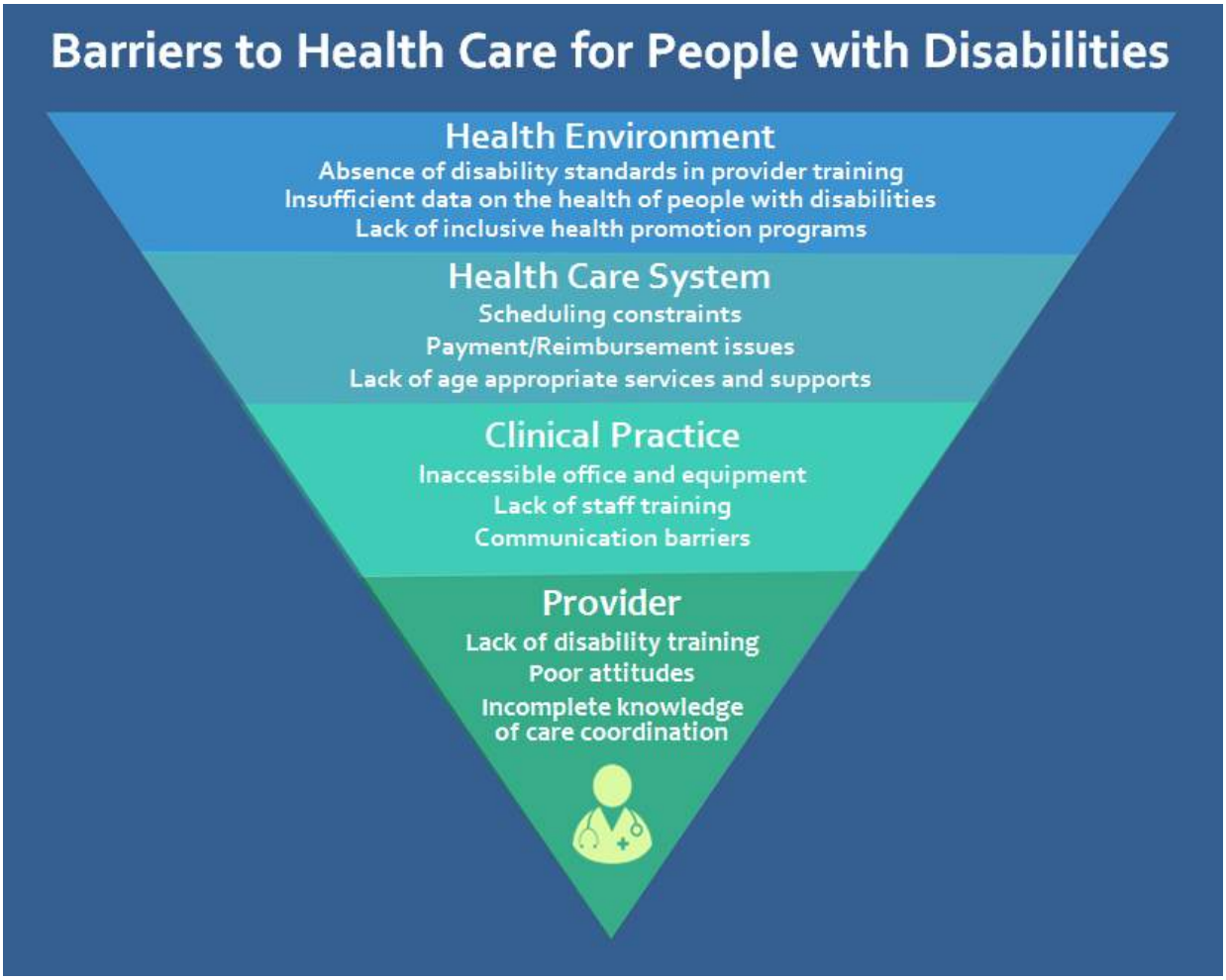


Image credit

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# Lesson 2: Disability: An overview

## Disability prevalence: One in four non-institutionalized adults in the United States has a self-reported disability [2]

## Section 2: Defining a disability

There are many different ways to define disability, and the term disability may have different meaning based on the setting. Consider some of the following settings and definitions through legal and conceptual models of disability, as well as the International Classification of Functioning, Disability, and Health (ICF). [3, 4]

LEGAL DEFINITIONS | CONCEPTUAL MODELS | ICF

- **Americans with Disabilities Act** (ADA) - "individual with a disability" is a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment. The ADA does not specifically name all of the impairments that are covered.
- **World Health Organization** (WHO) - Disability is part of being human. Almost everyone will temporarily or permanently experience disability at some point in their life. Disability results

from the interaction between individuals with a health condition...with personal and environmental factors.

- **Center for Disease Control and Prevention** (CDC) - A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).
- **Social Security Administration** (SSA) - For all individuals applying for disability benefits...the definition of disability is the same. The law defines disability as the inability to engage in any substantial gainful activity (SGA) by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death, or which has lasted or can be expected to last for a continuous period of not less than 12 months. A child under 18 will be considered disabled if he or she has impairments that causes marked and severe functional limitations.



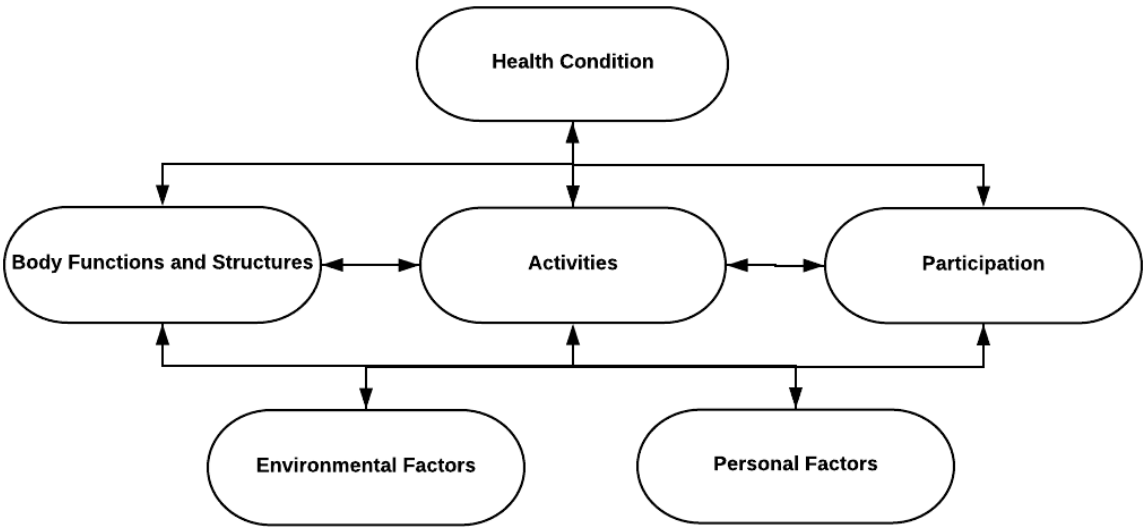
- **Social Model** - Disability is a result of social barriers rather than the impairments an individual may have. Theorizes that disability is not based on a medical condition, rather, the attitudes and structures within a larger society which create obstacles to participation.
- **Human Rights Model** - Involves social justice, policy, and the intersection of humans with disabilities within local and broader ecopolitical spheres and social groups, specifically related to human rights. This model is a proponent of human rights for all people, regardless of disability. It does not consider other identifying factors and systems which may be limiting
- **Ecological Model** - Consider the dynamic social interactions between the body, the individual with a disability, and the environment. This model focuses on the individual and their relationship with themselves and the broader world, though is more difficult to broaden to a group or population level.
- **Cultural Model** - An expansion on the social model of disability. Considers the cultural landscape where an individual interacts, such as an individual who is deaf and living in a primarily deaf community as nondisabled within their environment.

International Classification of Functioning, Disability, and Health (ICF)

This model utilizes a framework to describe and organize the relationship of function and disability. The ICF integrates many of the major models of disability, recognizing both an individual's health conditions and their effects as well as the relationship of the environment on disability.

The ICF model considers disability and functioning as **multi-dimensional** with the following factors:

- Body functions and structures
- Activities of people and the activity limitations they experience
- The participation or involvement of people in all areas of life and the restrictions they may face
- Environmental factors which affect these experiences (either as a facilitator or a barrier to participation)




CONTINUE

## Intellectual and Developmental Disabilities (IDD)

In addition to the general definitions of disability, there are different ways to define developmental disability (DD) and intellectual disability (ID). The terms disability, DD, and ID may have different meanings.
Often, Intellectual and developmental disabilities are recognized as a combined term, IDD or ID/D.

*Developmental Disability*

*Intellectual Disability (considered a subset of developmental disability)*

- Onset before age 22

- Is likely to continue indefinitely
- Affects 3 or more areas of life activities: Self-care, receptive or expressive language, learning, mobility, self-direction, capacity for independent learning, economic self-sufficiency

- Significantly reduced ability to understand new or complex information and to learn and apply new skills
    - Impairs ability to cope independently and occurs before adulthood

- Can be inherited or acquired
- Considered to range from mild to profound -> about 85% of individual with ID are considered to have mild ID

**Helpful tool for practice**

Visit this toolkit from the Vanderbilt Center to identify skills and needs people with IDD may have based on their degree of impairment [5]

READ MORE

CONTINUE

## Most common causes of IDD [6, 7, 8, 9, 10, 11]

### Cerebral Palsy

- A group of neurological disorders affecting body movement and muscle coordination caused by damage or abnormalities in the brain during development. This injury can occur during fetal growth or an injury before, during, or after birth
- Most common motor disability diagnosed in childhood, with a prevalence rate of 1 in 345 children (3 per 1,000 eight year olds) in the US
- There is a wide range of symptom severity, though all involve a level of difficult with both movement and posture related to voluntary movement (ataxia) and stiffness or exaggerated reflex (spasticity)
- 30-50% of individuals with CP have intellectual disability, and as many as 50% may have a co-occurring seizure disorder

### Autism spectrum disorder (ASD)

- A developmental disorder defined by deficits in communication and interaction, and restricted or repetitive behaviors and interests
- Typically, symptoms are present in the first three years of life
- *Additional information about ASD, diagnostic criteria, and prevalence will be found in lesson 3*

### Down syndrome

- Caused by extra copy of chromosome 21, DS is the most common chromosomal condition occurring in one in 775 births in the US (about 5,000 born with DS each year)
- Higher incidence of DS in an older mother
    - A 35-year-old maternal age has an incidence of 1 in 350, while a 40-year-old maternal age has an incidence of 1 in 100

- Results in intellectual disability, developmental delays, distinct physical features, and commonly occurring medical conditions including cardiac and digestive symptoms, and a higher risk of developing autoimmune conditions
- Resources for providers [12]

**Fragile X syndrome**

- A genetic condition from a mutation on gene FMR1 on the X chromosome
- Results in intellectual disability, behavioral, and learning challenges along with specific physical characteristics
- More frequently observed in males, and generally with greater severity
- Prevalence: Males – 1 in 4,000 to 1 in 7,000; Females – 1 in 6,000 to 1 in 11,000
- Resources for providers [9]

**Spina Bifida**

- Caused by a neural tube defect often during the first 28 days of pregnancy
- Most common permanently disabling birth defect, 166,000 individuals in US with this condition
- Very wide range of functional impairment. Severity is based on differences in the size of the neural tube defect, its location on the spine, and the size of the opening
- Resources for Providers [13]

**Fetal Alcohol Spectrum Disorders (FASD)**

- Previously known as Fetal Alcohol Syndrome
- A wide range of physical, behavioral, and cognitive impairments with secondary disabilities in medical, educational, mental health, and social domains
- Condition occurs when there is prenatal exposure to alcohol
- Estimated 1-5% of US first graders; the condition lasts through the lifespan

There are more causes of IDD than those above. You can learn more here. [13]

LEARN MORE


**Reflect on your learning and experiences.** You have a new

CONTINUE

# Lesson 3: Disability as a vulnerable population

The World Health Organization (WHO) and others recognize adults with disabilities as a vulnerable population. [14]

*Click on the tile to flip it over and see the answer.*

Risk for secondary conditions and comorbidities

Undiagnosed hearing or vision impairment, poor dental health, obesity, asthma

Age-related conditions

Diabetes, arthritis, cardiovascular conditions

Higher rates of premature death

Cancer, disproportionate mortality from COVID-19

Adults with disabilities **and** IDD are at an even greater risk.

**Cross-sectional analysis of the associations between four common cancers and disability 15**

Individuals who have a disability were found to have significantly higher rates for ovarian and prostate cancers than those without disabilities.

READ MORE

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**Don't forget - vulnerable and fragile are only medical terms. These terms do not encompass all the ways our patients engage in the world.**


CONTINUE

# Lesson 4: Autism spectrum disorder (ASD)

The DSM-5 restructured the diagnostic criteria for autism and prior related disorders. In DSM-4, there were five separate diagnoses considered under the category of Pervasive Developmental Disorders – Autistic disorder, Asperger Syndrome, Pervasive Development Disorder Not Otherwise Specified, Rett Syndrome, and Childhood Disintegrative Disorder. **Now, these disorders have been reclassified and combined into one label: autism spectrum disorder.**

You may have adult patients who were diagnosed with one of the previously separately identified diagnoses; these now all fall under the category of ASD. The DSM-5 identifies three levels of severity to provide additional information about an individual's ASD diagnosis. [16]

ASD is diagnosed based on core deficits in social communication and interaction, and restrictive or repetitive patterns of behaviors. A sensory processing component is also important to be identified.

| | |
|---|---|
| Level 1<br>Requiring support | • Difficulty initiating social interactions<br>• Unusual or unsuccessful responses to social advances made by others |

| | |
|---|---|
| | • May seem to have decreased interest in social interactions |



| | |
|---|---|
| Level 2<br>Requiring substantial support | • Delays in verbal and non-verbal communication<br>• Limited interest or ability to initiate social interactions and forming relationships with others<br>• Restricted interests and repetitive behaviors can be |



| | |
|---|---|
| Level 3<br>Requiring very substantial support | • Very limited initiation of social interaction with minimal responses to social interaction by others<br>• May be very limited in verbal communication<br>• Preoccupations, fixed rituals, and repetitive |

- Current prevalence rates for ASD as of 2022 are 1/31 eight-year-olds in the United States
    - Prior statistics have identified 1/36 and have increased to 1/31 -> Increase in case identification and diagnostics, consider a genetic component as well
    - Nearly 4 times more common among boys compared to girls of the same age
- Some cases have co-occurring ID, not always
    - Be cognizant of communication differences, where expressive and receptive language are not always aligned. An individual may not always be able to communicate expressively but still understand what you are saying!

**YOUTUBE**


## LISTEN Movie

A short film in which nonspeaking autistic people talk about how nonspeakers are represented in books, theatre, and film. They provide guidance for changing the narrative. Learn more and access transcripts, translations, and a toolkit here: https://communicationfirst.org/LISTEN/ Here's how it began: On December 24, 2020, the musician Sia publicly offered to fund CommunicationFIRST to make an introductory short to her new movie MUSIC.

**VIEW ON YOUTUBE >**

### Expand your knowledge with these ASD resources and advocacy groups:

**Autistic Self Advocacy Network (ASAN)** [17]

This organization is run by and for autistic people. They are a grassroots disability organization.

READ MORE

### Profound Autism Alliance [18]

This organization recognizes the unique challenges of people with profound autism and ID.

READ MORE

### Pennsylvania Autism Services, Education, Resources, and Training Collaborative (ASERT) [19]

ASERT is a partnership of medical, research, university, and provider groups to support individuals with autism and their families in PA.

READ MORE

### Association for Autism and Neurodiversity [20]

AANE provides individuals, families, and professionals with education, community, and support using a non-medical model for individuals to best access the support they need.

READ MORE

CONTINUE

# Lesson 5: Barriers to care and outcomes for people with ASD

Raymaker et al. (2017) [21] identified primary barriers to healthcare for adults with autism. These are the primary barriers which influence care for respondents, and ways to accommodate and provide a more positive experience for individuals with ASD at a provider visit.

### *Common barrier #1*

**Fear and anxiety**

- Allow for longer appointment times to build rapport with the patient
- Speak directly to the patient
- Explain or show the patient what will happen before it is happening

### *Barrier #2*

**Processing time**

- Ask questions in plain language
- Allow time to pass before asking another question
- Ask specific questions instead of open ended

*Barrier #3*

**Sensory sensitivites**

- Dim or turn off lights if possible
- Find a quiet exam room space
- Allow patient to stay in the clothing they arrived to an appointment in when possible
- Describe what you are going to do and obtain assent before touching a patient

*Barrier #4*

**Difficulty communicating with providers**

- Obtain a communication profile or preference prior to appointment if possible
- Speak directly to the patient even if they do not communicate verbally
- Ask the patient before communicating with a caregiver or care partner for support

- Provide visual aids as possible

**Raymaker** [21]

You can find the full study here.

READ MORE

CONTINUE

# Lesson 6: Additional barriers to care for people with IDD

- According to M.M. Stephens and K. Roseman in written communication (2024) through the FAB Center and colleagues working primarily with individuals with IDD estimate there is **at least 3 times the amount of paperwork** for patients with disabilities compared to those without
- Access to interdisciplinary teams improves quality of care
    - A social worker is critical to the care process for patients with IDD -> not all practices have a social worker available to them
    - Some individuals may have a case worker assigned to them by the state, however, this is not the case for all individuals
    - A workforce that understands disability will result in the provision of higher quality health care to individuals that will give person-focused support, access to care, health screenings, and a strong care team [22]
- Provider perceptions
    - Since the majority of physicians have not received disability-specific training, hesitancy in providing care is a barrier for individuals with IDD when seeking care

Test your knowledge: Let's examine the results of a study investigating the perceptions by physicians of people with disabilities.

*Match the statement on the left with your guess of the correct percentage on the right.*

*Drag and drop each box to match.*

---

| | | | |
|---|---|---|---|
| ≡ 1 | This percentage of physicians believe people with serious disabilities have a worse quality of life than those without. | 82.4% | ⌄ |
| ≡ 2 | This percentage of physicians felt very sure they could give the same quality of care to disabled patients. | 40.7% | ⌄ |
| ≡ 3 | This percentage of physicians strongly said they were happy to treat disabled patients. | 56.5% | ⌄ |
| ≡ 4 | This percentage of physicians thought the healthcare system often treats disabled people unfairly. | 18.1% | ⌄ |

SUBMIT

**Physicians' perceptions of people with disability and their health care** [23]

The perception of an individual's disability by a physician may impact fair health care for people with disabilities.

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Disability competent care [22]

CONTINUE

# Knowledge check and Section 1 conclusion

In this section, we covered topics including medical education and disability, an overview to disability, disability as a vulnerable population, ASD and barriers to care, and additional barriers to care for people with IDD. Please engage with the following questions to check your knowledge. To move on, you must score at least 80%.

*Question*

**01/05**

True/False. Medical education requires disability-specific education for students.

---

- ◯ True
- ◯ False

*Question*

**02/05**

Select all that apply. The ICF model of disability encompasses which of the following factors:

---

- [ ] Body functions and structures
- [ ] Activities
- [ ] Medications to manage symptoms
- [ ] Environmental factors
- [ ] Health conditions

*Question*

**03/05**

Most people with ID (85%) experience this level:

---

- ◯ Mild
- ◯ Moderate
- ◯ Severe
- ◯ Profound

*Question*

**04/05**

True/False. People with IDD are **less likely** to experience secondary complications from medical conditions and certain cancers.

---

- ◯ True
- ◯ False

*Question*

**05/05**

Select all that apply. Which of the following are considered **supportive factors** when completing a patient visit for someone with IDD?

---

- [ ] Longer appointment times
- [ ] Bright lights in the exam room
- [ ] Explaining what you will do before touching a patient
- [ ] Use of medical jargon
- [ ] Using visual aids to help demonstrate or explain concepts

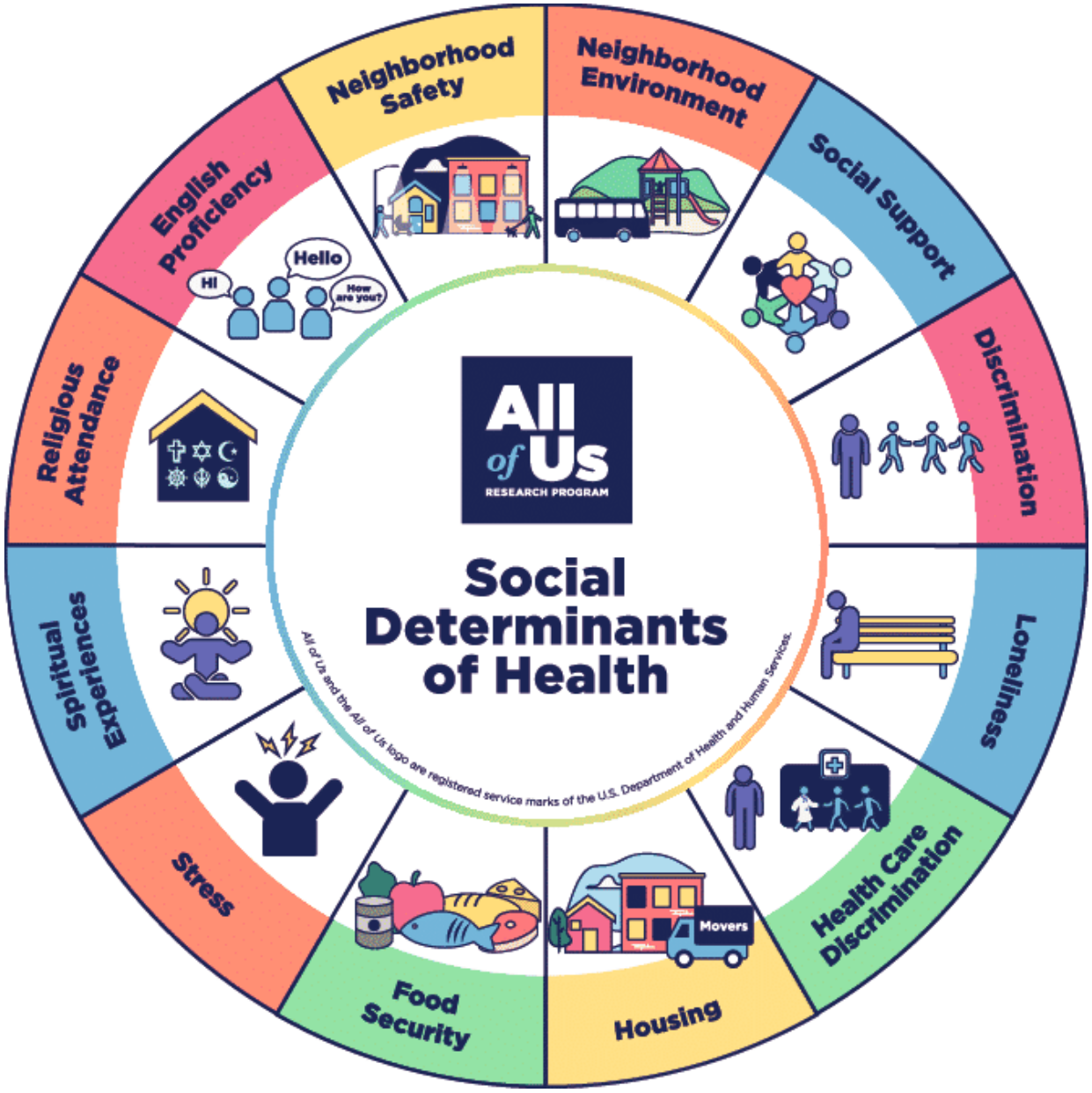
# Lesson 1: Social determinants of health

## What are social determinants of health (SDOH)?

SDOH refers to the health disparities which influence an individual's ability to access a healthy lifestyle. Factors are widespread and include areas such as income, access to quality healthcare, healthy foods, educational opportunities, and discrimination. [1]

Health outcomes and social factors are closely related, however, not often addressed together in health literature.

When an individual has a disability, there is a 'cascade effect' of some key SDOH which impact their ability to access positive health outcomes. [2]




All about the social determinants of health [1]

| | | | | | |
|---|---|---|---|---|---|
| | Individual person | → | Presence of disability | → | Underlying or comorbid condition |
| → | Access to care | → | Access to high quality care | → | Challenges with disease screening and prevention |
| → | Communication barriers | → | Lack of validated scales | → | Poor health outcome |

Example of a cascade effect from SDOH on a person with a disability

## Each piece acts in synergy and affect access to and quality of healthcare.

**A cascade of disparities: Health and health care access for people with intellectual disabilities** [2]

This article looks at studies from 1999-2005 on health differences for people with ID and identifies health differences, ways to help, and ideas for future research.

READ MORE


**Reflect on your learning and experiences.**
How can you address elements of the SDOH with an individual with IDD when you see them in

CONTINUE

# Lesson 2: Racial and ethnic differences

**Racial and ethnic health disparities among people with intellectual and developmental disabilities** [3]

Using national data, authors found that Latinx and Black adults with IDD had worse health outcomes compared to White adults with IDD, and those with IDD had worse outcomes compared to those without disability.

READ MORE

- While some factors lead to delayed care in the White group, the same factors led many Black and Latinx individuals to forego care altogether
- The authors suggested this may lead to additional preventable health problems in these two groups
- Future interventions aim to address institutional racism and develop trust between the racially and ethnically diverse disability and health professions in an effort to

reduce barriers to healthcare access for Black and Latinx individuals with IDD

This is an effort to be addressed at a systems level.

**Examining physician implicit racial bias against children** [4]

A study of 91 resident physicians found 91% had bias against Black children and 85% against Black adults.

READ MORE

**Complete a self-assessment**

You can visit the Harvard Implicit Association Test website to assess your own potential biases on a variety of attributes.

TAKE THE TEST

**A scoping review of health research with racially/ethnically minoritized adults with intellectual and developmental disabilities** [5]

Adults with IDD who are also in a racially or ethnically minoritized group may have overall worse health compared to their peers.

READ MORE

CONTINUE

# Lesson 3: Health disparities faced by patients with IDD

Individuals with IDD are **more likely** to have which of the following...
(select all that apply)

- [ ] Undiagnosed vision or hearing impairment
- [ ] Receive all preventative screenings
- [ ] Poor dental health
- [ ] Longer life expectancy
- [ ] Comprehensive sexual education
- [ ] Chronic disease (diabetes, arthritis, cardiovascular disease, asthma, obesity)

SUBMIT

Test your knowledge: What is the number one chronic condition in people with IDD?

- Obesity
- Cardiovascular disease
- Poor dental health
- Diabetes

SUBMIT

**Optimizing dental care for adults with intellectual and developmental disabilities: Challenges, strategies, and preventative approaches** [6]

Adults with IDD often face barriers to preventative dental care. This article investigates common causes and strategies to support oral health.

READ MORE

**For some individuals with IDD, sedation is necessary for thorough dental care.** Special Smiles, LTD is an outpatient dental facility in Philadelphia and New Jersey who provides comprehensive oral healthcare to individuals with IDD who require general anesthesia for their dental care. [7]

READ MORE

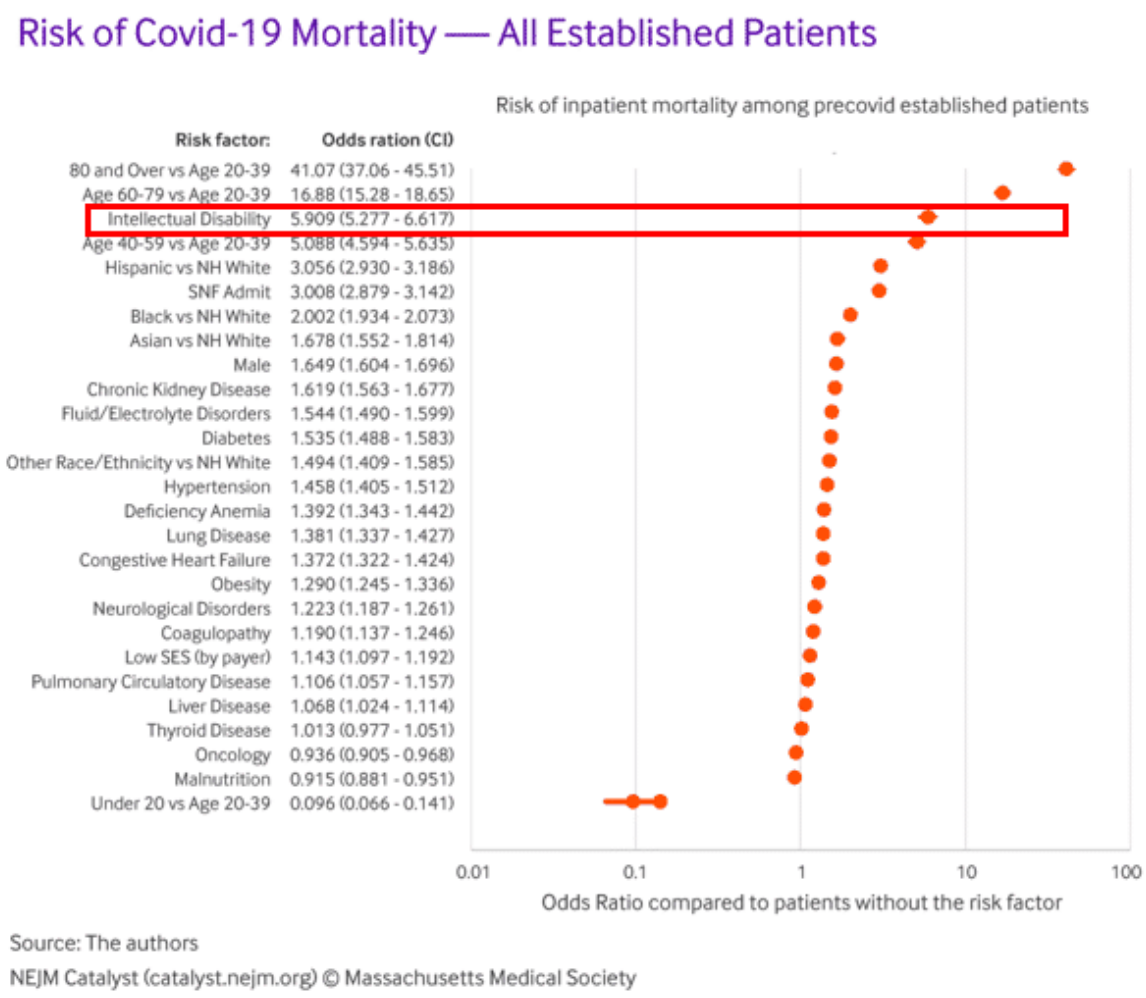
**A product recommendation for patients**: The Autobrush is a U-shaped toothbrush that goes in the mouth and cleans in 30 seconds. This could be a good tool for individuals with sensory sensitivity or limited mobility, or those who would like more independence in their oral hygiene routine.

LEARN MORE

CONTINUE

## Disproportionate mortality for individuals with IDD and COVID-19

Generally, the most common causes of death for individuals with IDD differ from the general population. They showed higher rates of mortality due to illnesses or conditions which are less likely to lead to death in the general population. [8]




Source: The authors



9

## Why was mortality so high for patients with IDD?[9]

- Rationing of care? Living factors? Ability to wear masks?
- Impossible to say for sure. However, there may be an element to consider related to how the healthcare system views and cares for individuals with IDD

## Code status disparity in patients with Down syndrome during the COVID era [10]

Findings:

- Respiratory infection is a known leading cause of mortality in patients with DS, and thus, perhaps a higher mortality rate from COVID-19 pneumonia is to be expected
- However, the data presented demonstrates that the odds of being made DNR on admission are out of proportion to the risk of mortality and that the diagnosis of Down syndrome is the greatest driver of DNR status after controlling for other risk factors


**Reflect on your learning and experiences.**
Knowing what you have learned so far and your own experiences with individuals with IDD, how

CONTINUE

# Knowledge check and Section 2 conclusion

This section covered health disparities faced and IDD. Topics included social determinants of health, racial and ethnic differences, and disparities faced by patients with IDD.

Check your knowledge with the following quiz. You must score at least 80% to move on.

*Question*

**01/04**

When an individual has a disability, there is _____ on some key social determinants of health, which impacts their ability to achieve positive health outcomes.

---

- ○ A negative spiral
- ○ A cascade effect
- ○ No impact
- ○ Support needed from their social network

*Question*

**02/04**

True/False. Patients with IDD experience additional barriers to care when they are part of a racial or ethnic minority group.

---

- ◯ True
- ◯ False

*Question*

**03/04**

While we can provide high quality healthcare to individuals with IDD who are part of a racial or ethnic minority group, large change must be addressed on a _____ level.

---

- ○ Community
- ○ Systems
- ○ Practice

*Question*

**04/04**

Select all that apply. Which of the following is considered a social determinant of health?

---

- [ ] Social support
- [ ] Food security
- [ ] Stress
- [ ] Neighborhood environment
- [ ] Health care discrimination

# Lesson 1: Underlying beliefs and ableism

Match the statistics - *Drag and drop to match*: In a survey of physicians who care for people with disability (excluding PM&R), and a survey of family and internal medicine residents 2019-2020[1, 2]...

| | |
|---|---|
| ≡ 1 Strongly agree that people with disabilities are unfairly treated in the health system | 18.1% |
| ≡ 2 Rate quality of life for people with disabilities as worse | 82.4% |
| ≡ 3 Remember any disability training in medical school | 34.6% |

SUBMIT

**"Without explicit disability training, healthcare providers are likely to view disability as a negative health outcome and to hold low expectations for the function and quality of life of individuals with disabilities." [3]**

## What is ableism?

Ableism is a form of discrimination against individuals with disabilities, built on assumptions that life without a disability is superior to life with one.

When people with disabilities rate their own quality of life, it is considerably high!

**Self-perceptions from people with Down syndrome [4]**

This study asked participants with DS to rate their own quality of life. Nearly 99% indicated they were happy with their lives, 97% liked who they are, and 96% liked how they look.

READ MORE


CONTINUE

# Lesson 2: Disparities related to diagnostic overshadowing

## What is diagnostic overshadowing?

The phenomena of physicians attributing non-specific symptoms to an individual's disability, halting further diagnostic investigation.

What happens when a clinician overshadows a patient's symptoms?

- Diagnostic delay leads to disease progression to a further stage before proper diagnosis
    - Higher rates of colorectal cancer, non-Hodgkin's lymphoma, prostate cancer, ovarian cancer
    - Later stage diagnosis is observed more often in individuals with movement difficulty and complex activity limitations [5]
- Sometimes, an increase in agitation in someone who has IDD is attributed to their diagnosis of IDD rather than a thorough investigation of their physical symptoms
    - There are case reports of missed GERD, aspiration, and cholecystitis, among others [6, 7]

What can you do as a provider?

**Be a detective!**

Do not assume a symptom or set of symptoms is due to an individual's disability.

And, do understand that an individual's disability might have unique secondary complication considerations.

The patient and those who support them are experts in their own care. If something is off to them, listen and investigate.

**Additional reading:**

**Diagnostic overshadowing in learning disability: Think beyond the disability** [6]

People with learning disability have an estimated lifespan that is 13 years lower for men and 20 years lower for women compared to the general population.

READ MORE

CONTINUE

# Lesson 3: The transition from pediatric to adult care for individuals with IDD

For many patients, the transition from pediatric to adult care leads to a reduction of previously offered services. Review the common challenges identified by patients with IDD who have transitioned from pediatric to adult care. [8]

CHAOTIC TRANSFER | LOSS OF COMPREHENSIVE INSURANCE COVERAGE | LACK OF ADULT PROVIDERS

- New providers are less familiar with the routines and accommodations to make visits successful
- Additional time needed to schedule and provide information to multiple providers about care needs
- New team is not always prepared for a longer or more complex medical history review

CHAOTIC TRANSFER | LOSS OF COMPREHENSIVE INSURANCE COVERAGE | LACK OF ADULT PROVIDERS

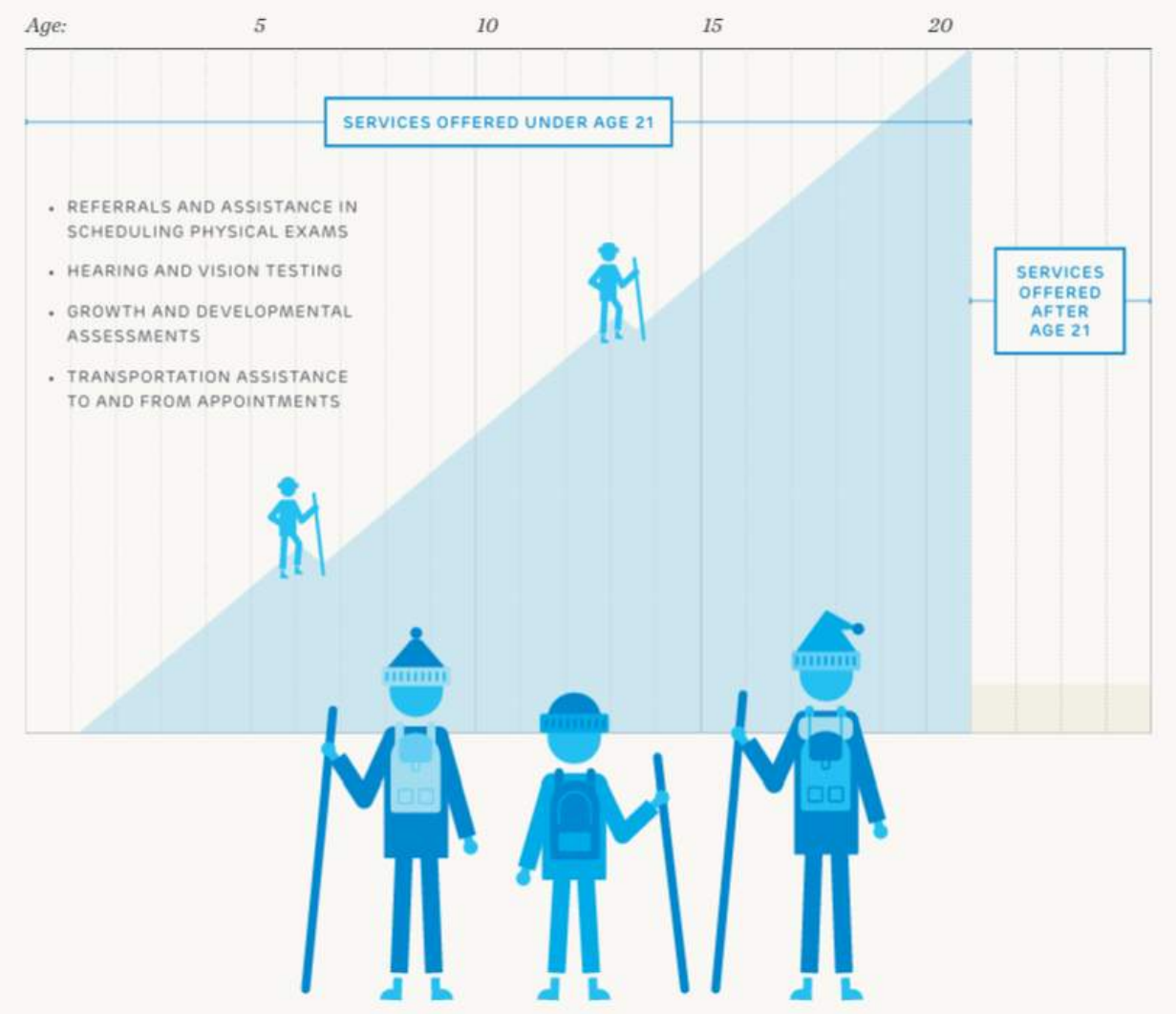
- During childhood, most patients with complex conditions are eligible for Medicaid to support their care needs

- Eligibility for comprehensive Medicaid ends at 21
- Social Security redetermines Social Security Insurance eligibility at age 18, using adult disability standards
    - 1 in 3 young adults typically lose their SSI benefits at this time
- Less education is provided on switching to an adult health insurance plan when coverage is lost

CHAOTIC TRANSFER | LOSS OF COMPREHENSIVE INSURANCE COVERAGE | LACK OF ADULT PROVIDERS

- When transferring from pediatric to adult care, it becomes the patient's responsibility to find a provider who has an understanding of their condition and care needs
- Multidisciplinary teams often found in children's hospitals do not generally exist in adult health care settings
    - When a patient would previously be able to have evaluations done by orthopedic surgeons, rehabilitation doctors, therapists, and dietitians all in one day, this now would require at least 4 separate appointments

## This transition is known as "the cliff"






CONTINUE

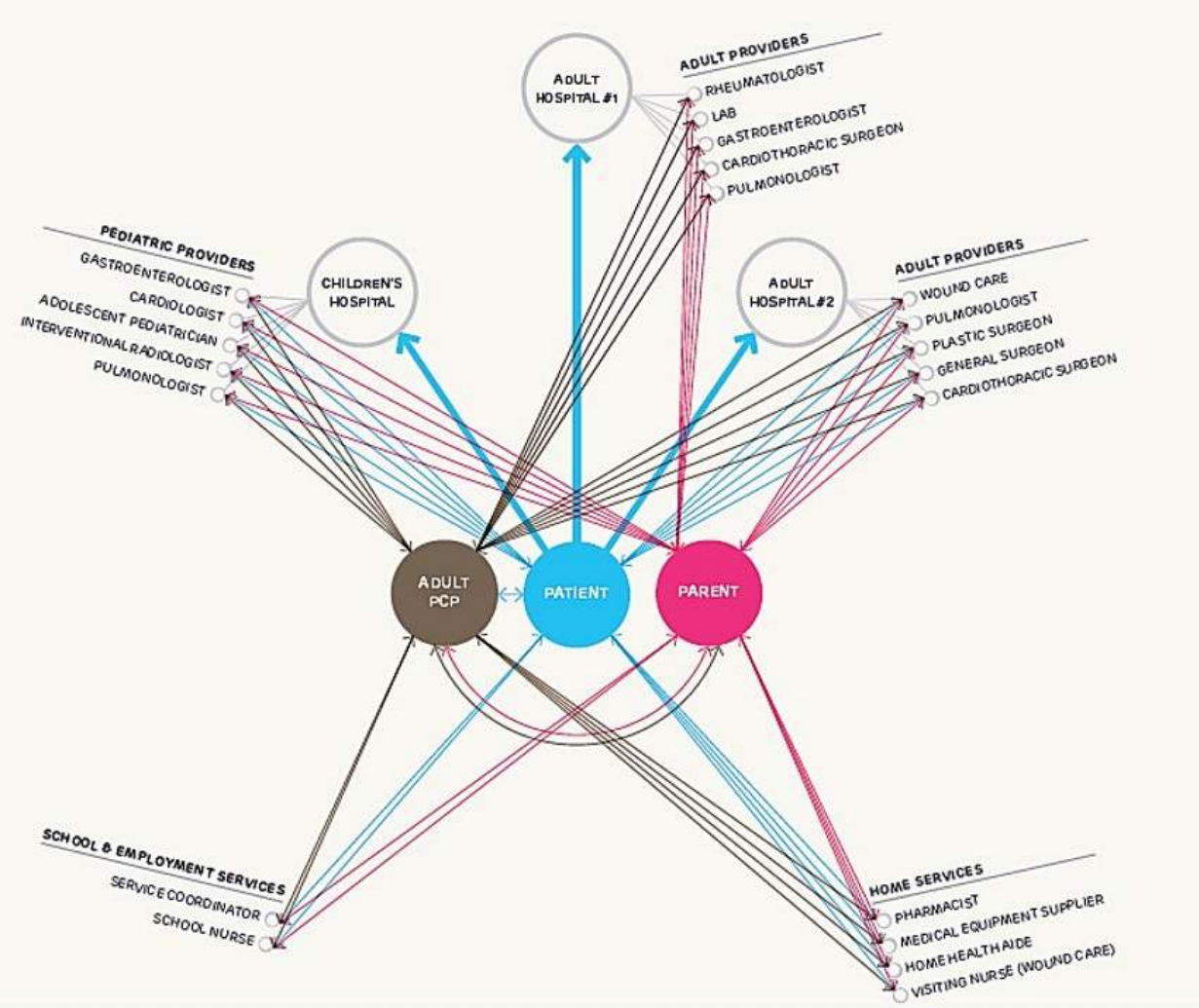
## When should we start transition planning?

Guess which age is considered best practice for transition planning conversations to begin.

---

- ○ Under 10 years
- ○ 12 years old
- ○ 14-16 years old
- ○ 6 months before the 18th birthday

SUBMIT






## Who should start the transition?

- A primary care physician is the best to happen first
- The primary care team can determine what can be managed internally and when to refer to specialists for other care
- Review the star chart to better visualize how complicated the transition to adult care can be for patients with IDD and complex needs

**CHOP Policy Lab - Transitioning to adult care: Supporting youth with special health care needs** [8]

LEARN MORE

**Managing complexity in care of patients with intellectual and developmental disabilities: Natural fit for the family physician as an expert generalist** [7]

A primary care physician is a good fit to address the complex care needs of individuals with IDD. Their ability to understand conditions, generalist skills, and strong relationship building skills make them a good care home for a complex patient.

READ MORE

CONTINUE

## Decision making

Decision making is another important part of transition planning which should begin before an individual turns 18.

Many times, teens may disappear from care for periods of time, and by the time they return are already 18.

Review the types of decision making below. [9, 10, 11]

### Power of attorney

- A Power of Attorney (POA) is established by an individual where they appoint someone to act as an equal decision maker in their presence or absence
- A POA can be established to make personal, financial, or medical decisions on behalf of the individual
- This option allows an individual to be able to make decisions for themselves, and allows the POA to make decisions on their behalf
- *Note: There are different levels of POA which can cover different aspects of a patient's life such as financial, health, mental health, and living decisions.*

### Guardianship

- This is considered the most restrictive option, for individuals who are unable to make care decisions for themselves
- An appointment of a guardian places all responsibilities and decision-making ability away from the person
    - This is completed by a court of law, and requires evaluation of the individual's ability to receive and evaluate information and communicate their decisions
- "Under the guardianship statute, the court has the power to place total control of a person's affairs in the hands of another. This great power creates the opportunity for great abuse" [12]

### Supported decision making

- Supported decision making allows for individuals to make their own choices with support from a team of people they trust and chose
- This is considered a less restrictive alternative to guardianships, where the person with a disability is part of the conversation to make choices for themself while also having the support of those around them
- **We all engage in supported decision making**. When we make big life decisions like a new job, a move, a big purchase, or even a new haircut, we discuss and consult with the important people in our lives who help inform us, then decide on our own

**The options for decision making described above are meant to provide an overview for providers to have knowledge of the ways an individual with IDD may be making decisions with their supporters.**


Start the transition process early!

Individuals should be part of their care process in a way that is meaningful to them.

CONTINUE

# Lesson 4: Communication as a primary tool

**The patient is an expert in their own care! Do not forget to include family members and caregivers, especially for patients who do not communicate verbally.**

Language is one of the most important ways to establish a basis of trust with your patients. Assume the use of person-first language, then ask a patient for their specific preferences.

**Practice using the examples below.** Drag and drop each item providing an example of language a provider should or should not use when speaking with, or referring to, a patient with IDD.
*Use your mouse to drag and drop the tile at the top to the correct pile.*

Do

An adult with Down syndrome

A 35-year-old female with cerebral palsy

A 56-year-old man with spina bifida

They have autism

Do not

He has Down's

The cerebral palsy lady

The wheelchair guy

## Also remember...

**Stay up to date!**

The term *mental retardation* is **outdated** and should not be used.

Update any potentially outdated materials in your practice to instead read cognitive or intellectual disability.

**Some nuance to consider:**

The autistic and deaf communities often prefer **identity-first language**

For example, deaf adult, autistic woman

However, this varies with individual preference

**Assume person-first language, then ask for more information.**

**If you make a mistake, that means you are human! Keep trying. Ask an individual for their preference, or follow their lead.**

TABLE 1

## Communicating Respect When Interacting with Patients with Developmental Disabilities and Their Supporters

| Common pitfalls | Respectful alternative |
|---|---|
| I can't imagine how hard it must be to be wheelchair-bound. | I'm glad to hear that expediting the repair of your electric wheelchair enabled you to return to church and work. |
| Your daughter is so lucky to have you. You're a super mom! | People with disabilities have a right to maximize their potential, and so do parents. What supports do you need? |
| **Communication** | |
| Speaking to the supporter: He's nonverbal? Can you tell me what brings him in today? | Speaking directly to the patient: Can you show me how you say yes? Can you show me how you say no? Are you in any pain or discomfort?* |
| Can you tell me what happened the last time he was in the emergency department? | Thank you for sharing that. I need a little more information. Is it okay if I ask your supporter? |
| **Supported decision making** | |
| Speaking to the supporter: Who makes her medical decisions? Does she have a guardian? | Speaking directly to the patient: Do you have a trusted supporter who helps you make medical decisions? |
| Have you looked into adult day care programs? | What are your interests? How would you like to spend your day? |
| **Health maintenance** | |
| Because you are at low risk of infection, we can skip doing a Pap smear. | Do you have sex? If so, do you have sex with men, women, or both? (Physicians should not assume that patients with disabilities have low risk of sexually transmitted infections.) |
| **Behavioral/psychiatric** | |
| Speaking to the supporter: He keeps banging his head. Have you spoken with a behaviorist? | Speaking directly to the patient: I see you're hitting your head. I haven't seen you do that before. Is something bothering you? |
| **Establishing baseline†** | |
| We don't have an accessible scale. Do you know how much you weigh? | We will record the weight of your wheelchair this visit, so that we can roll onto the scale in your chair next time. |
| **Sensory** | |
| Sorry you had to wait so long. | Because waiting is difficult for you, we scheduled your next visit for the first appointment of the day so that you can be seen right away. |
| **Pain assessment** | |
| The patient has a high pain threshold. (Information from the supporter.) | Speaking directly to the patient: Because you do not always show pain, let's try a regular schedule of a pain medicine to see if you improve. |
| **End of life** | |
| Because this treatment will not change your blindness or improve your intellectual disability, I recommend hospice. | Let me go over all of the treatment options with you. If you need time to think about it, we can record the information in plain language to review with your supporter at home. |

*—A video modeling a clinical interview with a nonverbal patient is available at https://www.mededportal.org/icollaborative/resource/904.

†—A tool for taking a history of baseline traits and characteristics is available at http://odpc.ucsf.edu/content/neurodevelopmental-profile-form.

Examples of improved communication during a provider visit [12]

## Think about these communication tips, directly from people with lived experience of disability (PWLE) and their caregivers.

- **Keep memory in mind**
  - When asking about how things have been since the last visit, or any changes in symptoms, a patient may not remember their history.
  - Some patients may only think in the "here and now" - be specific in the way you ask questions. Using answer choices can be helpful.
  - Keeping a conversation history of patient's experiences and interests can help build rapport over time.
- **Center the patient in the conversation**
  - If an individual needs support to respond to questions or give additional information, a caregiver or support person can be a helpful tool, but do not leave the patient out of conversation.
  - They are familiar with the words you are using and their lived experience, do not be condescending or leave them out.
  - Assume competence, even if a patient is not able to express their needs.

## Expand your knowledge and get involved with these disability advocacy resources:

National Disability Rights Network [13]

The NDRN is the U.S.'s largest provider of legal advocacy services for people with disabilities. Connect with your state affiliate for specific resources.

LEARN MORE

**The Arc of Pennsylvania** [14]

The Arc of Pennsylvania promotes access, civil rights, and inclusion for people with disabilities throughout the state. Connect with your local chapter for community-specific resources.

LEARN MORE

CONTINUE

# Lesson 5: Building rapport

## Relationship building is the key to success

Consider these key points as you review the following video clips.

- Always speak directly to the patient
- Speak to the patient as they are an adult, not like they are a child
- Use plain language. If using medical jargon, explain what terms mean
- Explain procedures or exam elements before they happen
- Use concrete language (ex. Pick up your jacket and wait by the door vs. "get ready")
- Avoid shouting
- Allow additional processing time when asking questions or for assent

Each video[15, 16] will have a reflection question for you to consider.

Inclusive Health: Caring for Patients with Intellectual Disabil…

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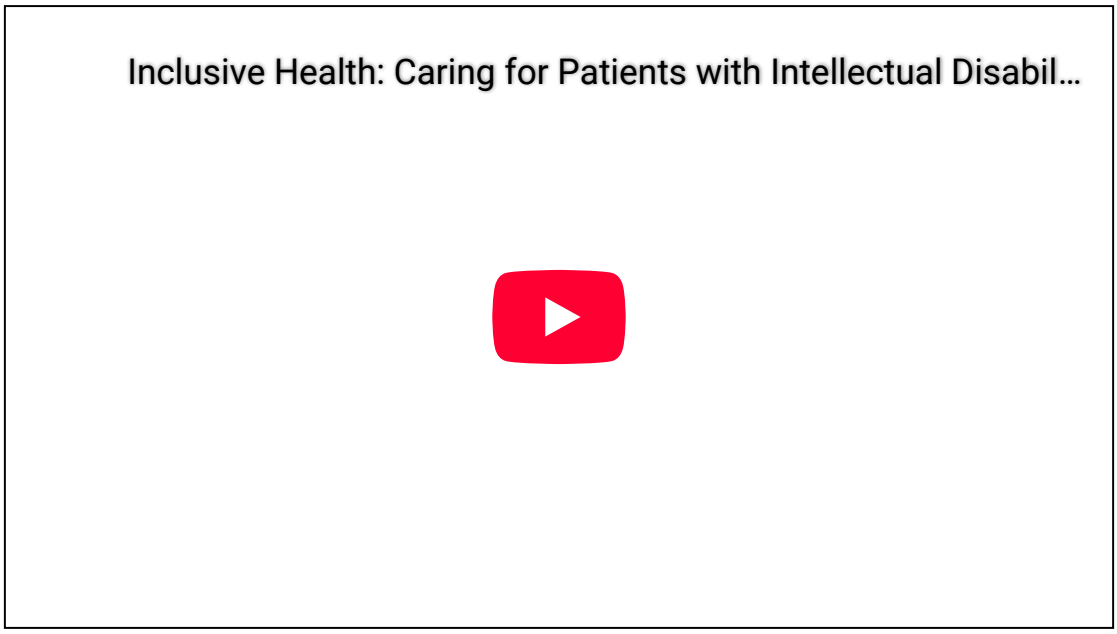
**Watch the video above, then reflect.** What did the staff member in this video do to make the patient feel more comfortable?



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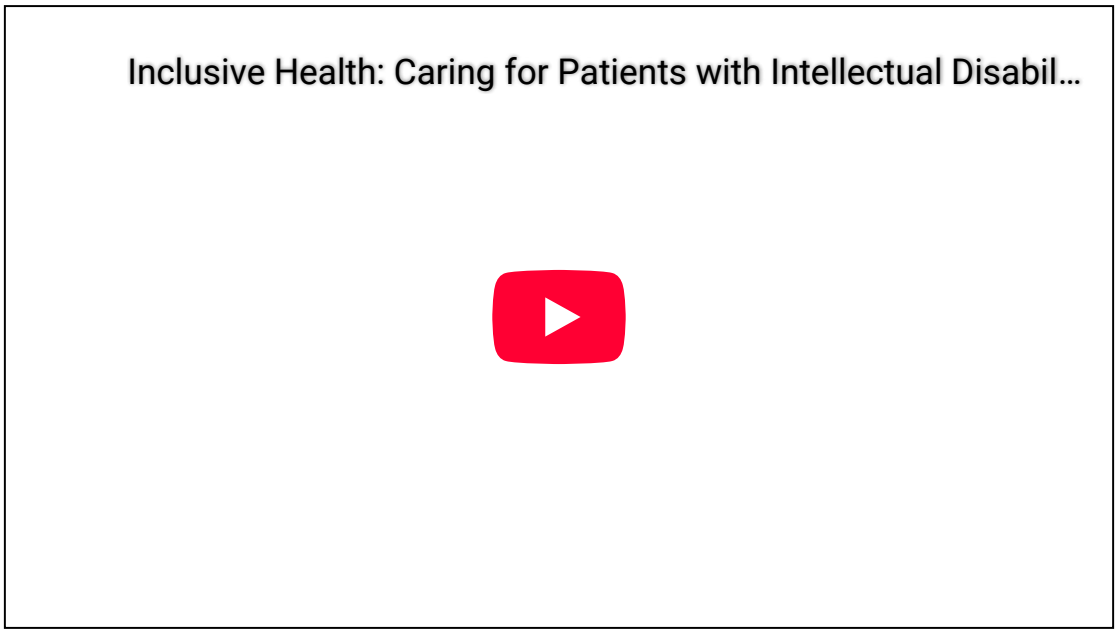
**Watch the video above, then reflect**. What did this provider do well? What are two other examples of concrete questions the provider



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**Watch the video above, then reflect.** What are ways you can provide information to a patient before touching them or doing an exam? What is

## Think about these tips, directly from people with lived experience of disability (PWLE) and their caregivers.

- **Allow the patient to be their own expert**
    - People with cerebral palsy or other movement disorders may move in a different or unexpected way than you may expect.
    - Do not provide help unless it is asked for or the person has given consent. Just because a movement pattern or transfer may look unsafe or
- **Tell-show-do is very impactful**
    - This method helps reduce the anxiety an individual might have about a procedure, and allows a provider to explain what will happen.
    - Do not be afraid of using medical jargon - however, define the terms you are using and use a visual or a tactile model when possible. Patients have often heard these terms and are familiar with their own condition.

unconventional, does not mean
it is.

CONTINUE

# Lesson 6: Supportive tools for visits

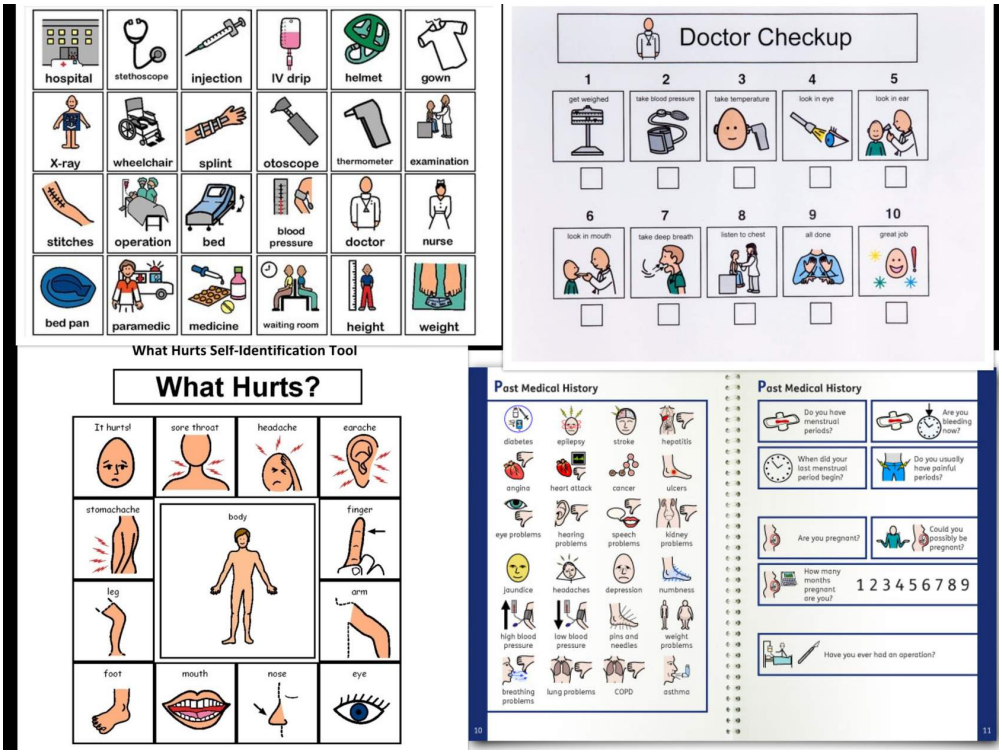
## What can you add to your practice to be more supportive of patients with IDD?

There are a variety of accommodations which can be supportive of serving more patients with IDD. This lesson will highlight some physical additions, as well as office policies.

Be an agent of change in your practice! Additional tools can be found in the post-module resources.

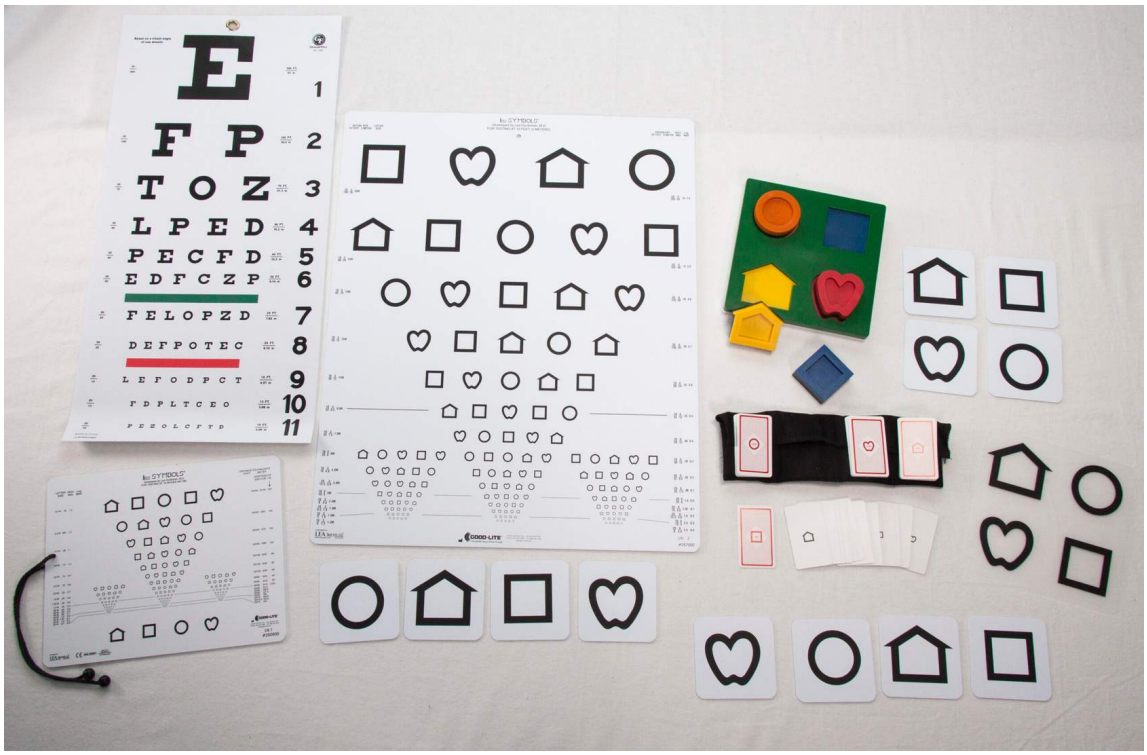
### Visual aids

- Information can be provided to a patient ahead of time to prepare them for what the office may look like
- Visual aids can be used within a visit to highlight the general order of visit (ex. weight, blood pressure, temperature, discussion with provider, physical exam)
- For patients who may not communicate verbally, a visual can be supportive in gathering more information about their signs and symptoms
- Visuals are especially helpful for some people with IDD to increase their understanding. Consider the use of pictures or use a physical model to demonstrate when explaining\
- Review examples [17]




### Visual Snellen chart

- A visual screen is required for athletes as part of Special Olympics
- A picture-based Snellen chart is a low-cost option that does not require verbal responses, or identification of letters




### Wheelchair scale

- Some patients haven't had a weight check completed in years if their physician offices do not have a wheelchair scale
- Best practice: On a patient's first visit, after they transfer to the exam table, weigh the chair by itself. Then after having the chair weight, the patient can be weighed in the chair in all future visits
- It is important to have an accurate weight for medication dosing and physical health
- *Image alt text: A man is sitting in a wheelchair on a floor-level scale. He is wearing a navy sweatshirt and a baseball hat.*


### Considerations for low vision

Low vision can be a co-occurring condition for some individuals with IDD.

- Describe yourself, any other people who may be in the room, and your environment to the patient
- Include physical or tactile models of body parts as possible for increased sensory feedback and to support understanding
- Allow the patient to touch or hold tools used in the exam or procedure prior to them being used to reduce anxiety and increase knowledge
- Offer magnifiers in the office for materials
    - Be sure to offer printed materials with large font and high contrast to increase readability

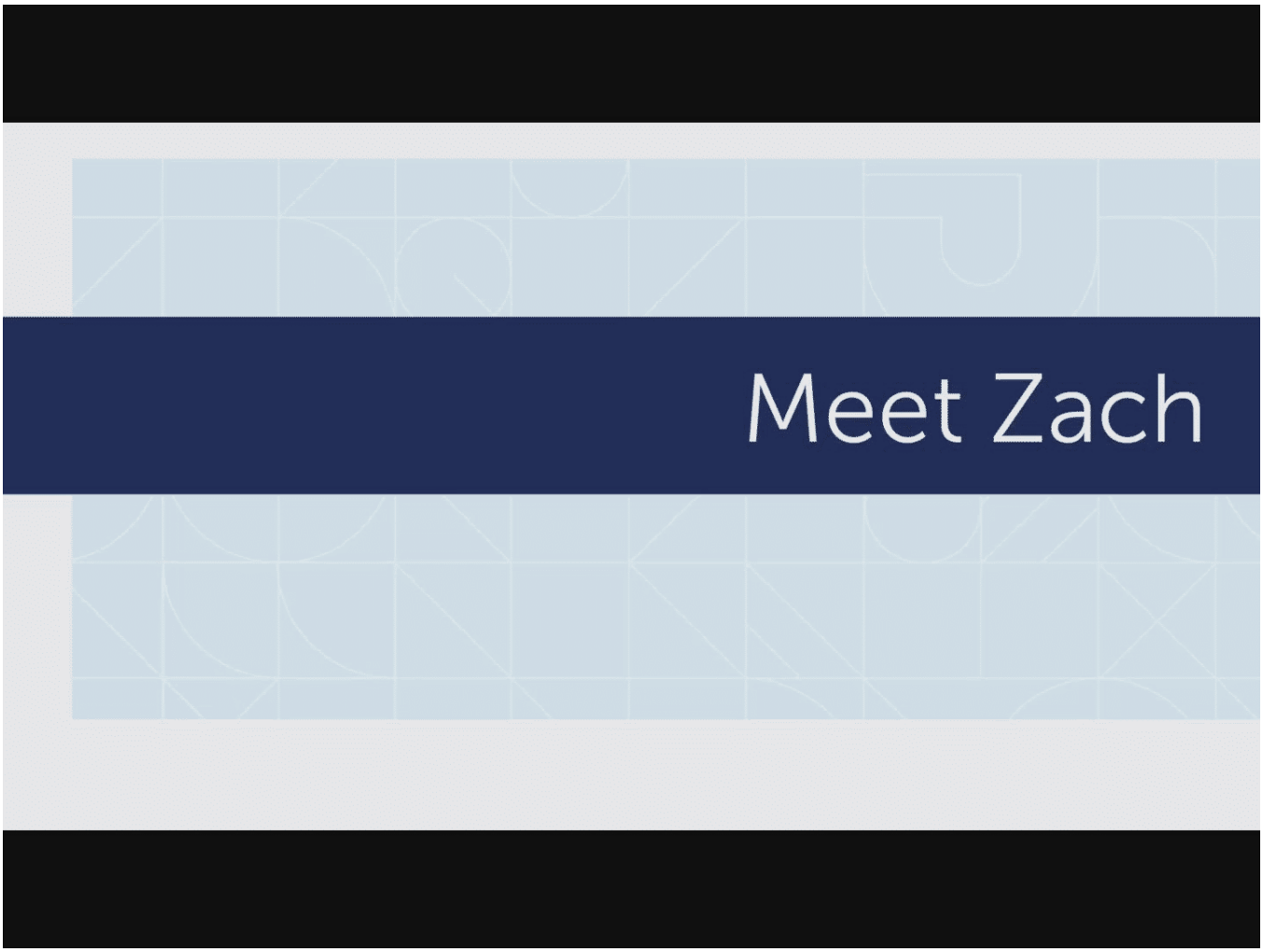
- Be mindful if an individual has a service animal
    - Do not interact with the animal, as they are working
    - A service animal is allowed to be present in a patient's appointment
    - Learn more about Service animals from the ADA

**Office policy accommodations**

- Extended visit time
    - Complex patients will require extra time for visits! Not being rushed will allow for better care, rapport building, and addressing all needs in the visit
    - If extending a visit is not possible, book a patient for a double-block so they can receive extra time to talk to their provider
- Late policy
    - Consider your practice's late policies. If you can be flexible, do! Consider the patient's journey to get to your appointment
    - Review Zach's video below
- Staff etiquette and education across roles
    - All members of the team contribute to a positive patient experience and ease for a patient with IDD
    - Consider if a patient needs to wait in the waiting room or can be brought right back, paperwork completed ahead of visit, and scheduling
- Be available to patients for follow up questions or comments

- Many providers use online MyChart for communication
- Remind patients they can follow up through this channel, or they can share information prior to their visit

## Learn from Zach about getting ready to leave the house for an appointment

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# Knowledge check and Section 3 conclusion

This section covered practical strategies for caring for patients with IDD. Ableism and diagnostic overshadowing, transitioning from pediatric to adult care, the use of communication and rapport, and supportive tools for visits are important to consider in caring for complex patients.

The following quiz will be the final knowledge check of this module.

*Question*

**01/05**

Proper disability training for healthcare providers supports...

---

- **Negative** health outcomes and **positive** expectations for function and quality of life for people with IDD.
- **Positive** health outcomes and **positive** expectations for function and quality of life for people with IDD.
- **Positive** health outcomes and **negative** expectations for function and quality of life for people with IDD.
- **Negative** health outcomes and **negative** expectations for function and quality of life for people with IDD.

*Question*

**02/05**

Select all that apply. Diagnostic overshadowing results in which of the following:

---

- [ ] Further progression of disease
- [ ] Missed diagnoses wrongly attributed to IDD
- [ ] A comprehensive, thorough examination
- [ ] Higher rates of certain cancers

*Question*

**03/05**

Select all that apply. What categorizes "the cliff" in the transition from pediatric to adult care?

---

- [ ] Change in primary care provider
- [ ] Moving to a new home or residence
- [ ] Loss of access to certain multidisciplinary services
- [ ] Change in the diagnosis of IDD
- [ ] Insurance changes
- [ ] A change in decision making powers

*Question*

**04/05**

Which of the following is recommended language for a patient you have not met before?

---

- The Down's guy, Josh. He's autistic, too. He's 27 years old.
- Josh is 27, is Down syndrome, and is autistic.
- Josh is a 27-year-old man with autism and Down syndrome.

*Question*

**05/05**

What is an example of concrete language?

---

- [ ] Pick up your jacket from the chair in the corner.
- [ ] Your room is over there, a stone's throw away.
- [ ] Hop on up and show me what you've got.
- [ ] When you leave the room, walk to your left until you get to the door. A nurse will be there to help you.

# Conclusion of Module 1

## Conclusion

Thank you for participating in module 1, Communication, common sense, and nuance: Care of patients with IDD. This is part 1 of a 4-part education series funded by PADDC. Additional information related to this project can be found on the project website.

Please complete the post-module satisfaction survey below in order to provide information to PADDC for reporting purposes.

Thank you for your support, engagement, and interest in increasing high quality care for patients with IDD. Please review the additional resources below after completing the survey and share this module with your colleagues!

For continued discussion, you may visit our live discussion board page here.

Jefferson
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This survey will take 2-5 minutes to complete.

For each question, please choose the categories

PDF **References Module 1__.pdf**
204.5 KB

PDF **Module 1 Additional Resources__.pdf**
186.5 KB

**Module 1 learning objectives review**

- Discuss barriers and pitfalls for youth with intellectual and developmental disabilities (IDD) transitioning from pediatric to adult care

- Apply strategies for involving individuals with IDD in achieving their healthcare goals and maximizing their outcomes

- Discuss decision making in advance of the 18th birthday for all patients with IDD

- Identify practical strategies to consider for office visits

Thank you for your participation!