

FACILITATOR GUIDE

SECTION 1: UNDERSTANDING INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Developed by



Section 1

Understanding Intellectual and Developmental Disabilities (I/DD)

Objectives:

After this training, participants will understand what Intellectual and Developmental Disabilities are, characteristics of common diagnoses, and general guidelines for interacting with individuals.

- Participants will be able to explain the difference between intellectual and developmental disabilities.
- Participants will be able to identify various I/DD diagnoses and state their characteristics.
- Participants will be able to differentiate between developmental and chronological age and the unique challenges it presents to a clinical setting.

Section Files:

PowerPoint

Rise Course

Script

Participant Resources

Activity Resources

Other Sections:

01 Introduction to Intellectual and Developmental Disabilities

02 Trauma-Informed Care for Individuals with I/DD

03 Assessing and Treating Mental Health Issues in Individuals with I/DD

04 Navigating Appointments with Individuals with I/DD

05 Crisis Prevention and Intervention

Outline:

What is I/DD?

- a) **Differences between Intellectual and Developmental Disabilities**
 - i) Definition and Characteristics of ID and DD
 - (1) Intellectual Disabilities
 - (2) Developmental Disabilities
 - ii) Causes
 - iii) Diagnosis
- b) **Statistics of I/DD and Mental Health**
- c) **Examples of common I/DD diagnoses and considerations for the clinical setting**
 - i) Autism
 - ii) Down Syndrome
 - iii) Cerebral Palsy
 - iv) Fetal alcohol spectrum disorders
 - v) Tourette syndrome - neurodiversity besides autism
 - vi) Other Common Diagnoses
 - (1) Fragile X
 - (2) Prader-Willi
- d) **Hidden/Invisible Disabilities in the I/DD context**
- e) **Developmental Considerations in the Clinical Setting**
 - i) Chronological versus Developmental Age

Section 1 Facilitation Schedule – 60 mins total

Introduction

- **Opening activity - 5 mins**
Sticky Note Activity, Instructions in Slide 1 & in Facilitator's Guide
- **Introductions - 5 mins**
Participants share name and role within organization – I would like to change this to a Connection Question connected to the sticky note activity

Presentation Introduction to I/DD – 30 mins approximately

- **Share out: 3-5 mins**
Questions and things that stood out

Materials & Prep

Materials Needed:

- ☐ Flip Chart Paper
- ☐ Sticky notes
- ☐ Pens
- ☐ Participant Guides
- ☐ Extra paper

General Prep:

- ☐ Print Activity 2 Sheets – there are 5 different sheets and should be groups of 4-5, depending on the number of participants, duplicates of the sheets might be needed.
- ☐ Flip Chart Paper with the different Brainstorming categories should be placed around the room before the session starts.

Categories

- What they know about Individuals with I/DD or implicit biases many people hold about them
- Fears they have surrounding interacting with and providing services to Individuals with I/DD
- Concerns they have with Communication
- Miscellaneous

Quick Guide: Introduction to I/DD

Big Idea:

Intellectual and Developmental Disabilities split into two different sub-categories. By understanding the characteristics of Intellectual Disabilities and Developmental Disabilities, more individualized care can be given. Emphasis should be on the uniqueness of each individual and that, despite significant challenges, they are capable of achieving significant milestones and goals through support. This is just an introduction. Topics will be covered in depth in the following sections.

Timing: approx. 40 minutes to cover slide material, leaving 20 mins for activities, questions, and break before the next section.

Part 1: Introduction to I/DD		Timings: 60 mins total	
Opening	6 slides	10 mins	<u>AM/PM</u>
a) Differences between Intellectual and Developmental Disabilities	12 slides	15 mins	
i) Definition and Characteristics of ID and DD			
(1) Intellectual Disabilities			
(2) Developmental Disabilities			
ii) Causes			
iii) Diagnosis			
b) Statistics of I/DD and Mental Health	5 slides	5 mins	
c) Examples of common I/DD diagnoses and considerations for the clinical setting	12 slides	15 mins	
i) Autism			
ii) Down Syndrome			
iii) Cerebral Palsy			
iv) Fetal alcohol spectrum disorders			
v) Tourette syndrome - neurodiversity besides autism			
vi) Other Common Diagnoses			
(1) Fragile X			
(2) Prader-Willi			
d) Conclusion	7 slides	15 mins	<u>AM/PM</u>
i) Hidden/Invisible Disabilities in the I/DD context			
ii) Developmental Considerations in the Clinical Setting			
iii) Closing activities and break			

01 OPENING SLIDE

Facilitator's Notes

Slide Text:

Welcome to our five-part training on working with individuals with an Intellectual and Developmental Disabilities diagnosis.

Introduce self:

This training was developed by Woods System of Care under a grant funded by NJCDD to provide insight, guidance, and recommendations for providing safe, thoughtful care to individuals with IDD.

Timing: 1 min



Do:

- This slide should be up as participants are entering and getting settled
- Consider having some music playing in the background
- Welcome Participants

Material Notes

Throughout the facilitator's guide, in this section we will include additional information and references so that you can continue to learn and be able to provide participants with additional information as needed.

Trainer Notes:

02 SECTION SLIDE

Facilitator's Notes

Slide Text:

Speaker Script:

This training will be broken into 5 one-hour sections.

Section 1: Understanding Intellectual and Developmental Disabilities (I/DD)

Section 2: Trauma-Informed Care for Individuals with I/DD

Section 3: Assessing and Treating Mental Health Issues in Individuals with I/DD

Section 4: Navigating the Appointment

Section 5: Crisis Prevention and Intervention as Part of the Support Team

By the end of this training, we hope that you will feel more confident working with individuals with I/DD and have concrete ideas for making the appointment go smoothly, creating and communicating a treatment plan, and utilizing resources for broadening your understanding of this community.

Timing: .5 min



Do:

This slide should just be briefly touched on

Material Note:

Trainer Notes:

03 ACTIVITY Sticky Note Brainstorm

Facilitator's Notes

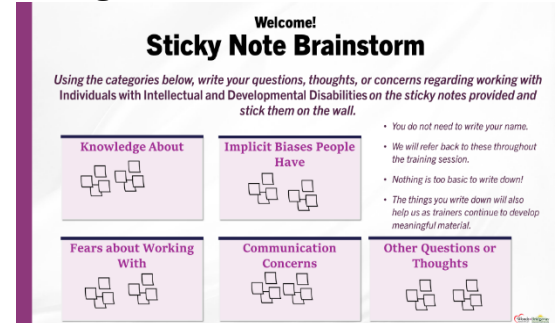
Activity 1: Sticky Note Brainstorm

DIRECTIONS

1. Before the training, have enough sticky note pads for each participant, plus pens.
2. Pass out sticky note pads to participants.
3. Instruct the participants that they should brainstorm questions, thoughts, concerns, etc. regarding working and interacting with Individuals with Intellectual and Developmental Disabilities. Reassure them that this is a safe space and their names aren't going on the sticky notes.
4. They can brainstorm what they know according according to these categories:
 1. What they know about Individuals with I/DD and Autism
 2. Implicit biases many people hold about that population
 3. Fears they have surrounding interacting with and providing services to Individuals with I/DD
 4. Concerns about Communicating with Individuals with I/DD and Autism
 5. Other Questions
5. Then, they should put their sticky notes on the wall.
6. Share that, over the course of this training, you hope that these questions and concerns will be addressed, and that the notes will be re-addressed throughout the trainings.

Trainer Notes:

Timing: 5 mins



Do:

- Have sticky notes and pens ready at participant tables
- Have a board or wall area available for participants to put sticky notes
- This activity can happen before or after the training has started. See notes in Activity instructions at the end of the guide

Material Notes:

04 INTRODUCTION

Facilitator's Notes

Introductions

Slide Text:

Click for Question to Appear

Turn to the person next to you and share

“If you were a holiday, what holiday would you be and why?”

Purpose:

Thinking outside the box, something we will need to do a lot of today.

Rethinking things in a new light is a valuable skill.

Participants share name and role within the organization.

Timing: 1 min



Do:

- Question appears on click
- “If you were a holiday, what holiday would you be and why?”

Material Notes

Question can be changed as you desire to suit the specific training.

Trainer Notes:

05 AGENDA

Facilitator's Notes

Speaker Script:

In this training, we are going to discuss and define I/DD, share common diagnoses of I/DD, and discuss basic considerations for treatment and consultation in the clinical setting.

Timing: .5 min



Do:

Material Notes:

Trainer Notes:

06 OBJECTIVES

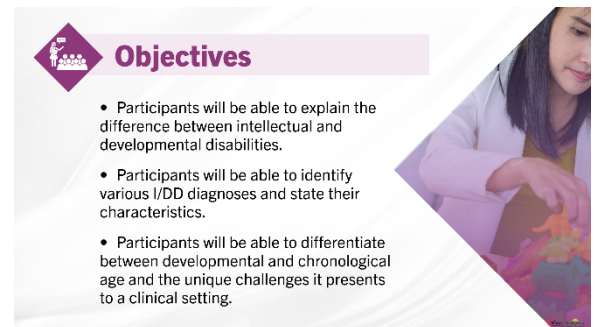
Facilitator's Notes

Speaker Script:

After this training, you will be able to:

- Explain the difference between intellectual and developmental disabilities.
- Identify various I/DD diagnoses and state their characteristics.
- Differentiate between developmental and chronological age and the unique challenges it presents to a clinical setting.

Timing: .5 min



Do:

Material Notes: *This slide can be skipped*

Trainer Notes:

07 WHAT IS I/DD

Facilitator's Notes

Speaker Script:

The abbreviation I/DD stands for Intellectual and Developmental Disabilities. This term covers a broad spectrum of conditions that impact individuals in different ways. It's important to recognize that no two people with I/DD are the same. Their abilities, strengths, and challenges can vary widely, which is why understanding and interacting with each person as a unique individual is crucial for providing effective support.

Timing: .5 min



Do:

Material Notes:

Emphasize looking at the whole person and their uniqueness.

Trainer Notes:

08 DIFFERENCES BETWEEN DD & ID

Facilitator's Notes

Speaker Script:

We will watch a short video explaining the differences between intellectual and developmental disabilities.

Video

<https://youtu.be/rymHXQmiugI?si=BOwf2EcNO9nXjs1e>

(Psych Hub, 2021)

Timing: 4 min



Do:

Material Notes:

If you would rather not watch a video, there are slides at the end of the training that can be used to talk through the differences between ID and DD.

Trainer Notes:

09 INTELLECTUAL DISABILITIES

Facilitator's Notes

Speaker Script:

Intellectual Disabilities, as mentioned earlier, impact a person's cognitive functions, affecting their ability to learn, reason, communicate, socialize, or care for themselves.

Timing: .25 min



Material Notes:

The following 5 slides are a recap of the video and basic information on I/DD. They are a good opportunity to take questions and clarify any misunderstanding on what I/DD is.

10

Facilitator's Notes

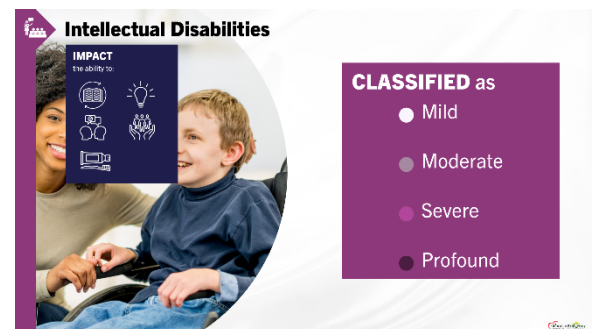
Speaker Script:

Intellectual Disabilities are often classified as Mild, Moderate, Severe, or Profound, depending on the level of impact on the individual. Intellectual disabilities appear before the age of 18 and should be diagnosed before the age of 22.

The majority of diagnoses are mild. Most likely, the people you are going to see will have a mild classification, and there is a chance they might not even be diagnosed.

(Community Based Care, IDD Supports, 2024)

Timing: .5 min



Trainer Notes:

11 INTELLECTUAL DISABILITIES

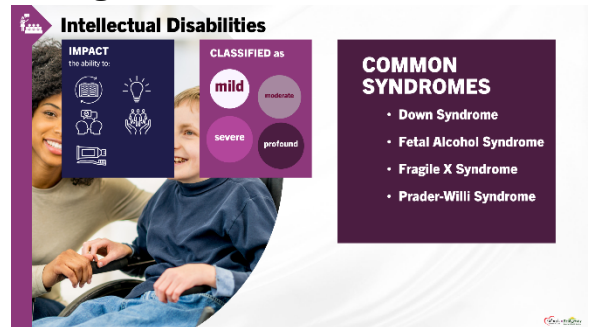
Facilitator's Notes

Speaker Script:

Some common syndromes associated with Intellectual Disabilities include Down Syndrome, Fetal Alcohol Syndrome, Fragile X Syndrome, and Prader-Willi Syndrome. These are just a very few of the many different I/DD diagnoses that exist. Often, there might be nothing more than just a generic intellectual disability diagnosis without a specific cause.

(Community Based Care, IDD Supports, 2024)

Timing: 4 min



Do:

Material Notes:

Trainer Notes:

12 DEVELOPMENTAL DISABILITIES

Facilitator's Notes

Speaker Script:

Developmental Disabilities encompass a wider range of conditions. They include Intellectual Disabilities, but also physical disabilities that may not affect cognitive functioning.

These disabilities usually appear during the developmental period of a person's life and result in some level of functional limitation in movement, learning, language, self-help, independent living etc.

These limitations last their entire lifetime.

Timing: .5 min

**Developmental Disabilities**

IMPACT
the ability to:

 learn

 move

 language

 self help

 independent living



Do:

Material Notes:

13

Facilitator's Notes

Speaker Script:


Some developmental disabilities, such as blindness or muscular dystrophy, affect only physical development.

Other conditions, like Epilepsy and Cerebral Palsy, affect physical development but don't necessarily imply intellectual differences, although they can be present.

Neurodevelopmental Disorders affect brain development, but not necessarily cognitive functioning. These include Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD).

Some of these conditions can occur simultaneously, which complicates treatments and interventions. For example, someone diagnosed with ASD can also be diagnosed with ADHD.

Timing: 1 min

**Developmental Disabilities**

COMMON DIAGNOSES

Physical Development

- Muscular Dystrophy
- Blindness


Physical Development and Potentially Cognitive Functioning


- Cerebral Palsy
- Epilepsy


Brain Development and Potentially Cognitive Functioning


- Autism Spectrum Disorder


IMPACT
the ability to:


 learn

 move

 language

 self help

 independent living



Do:

Material Notes:

Trainer Notes:

14 CAUSES OF I/DD

Facilitator's Notes

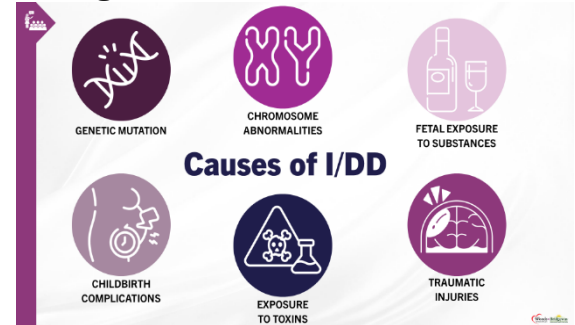
Speaker Script:

The causes of Intellectual and Developmental Disabilities are varied and complex. They include:

- genetic mutations,
- chromosome abnormalities,
- exposure to substances during fetal development,
- traumatic injuries,
- exposure to toxins,
- environmental factors, and
- complications during childbirth or early childhood.

Understanding these causes is essential for prevention and early intervention.
(NIH, 2021)

Timing: . 5 min



Do:

Material Notes:

Trainer Notes:

15 BODY SYSTEMS AFFECTED BY I/DD

Facilitator's Notes

Speaker Script:

Despite the differences between Intellectual and Developmental Disabilities, there are commonalities in how they affect the body. It can be helpful to think about them in terms of the body systems they impact:

Metabolism: Disorders that impact how the body uses food and energy can affect overall body and brain functions.

Nervous System: Disorders affecting the brain, spinal cord, and nervous system can lead to challenges in intelligence, learning, and behavior.

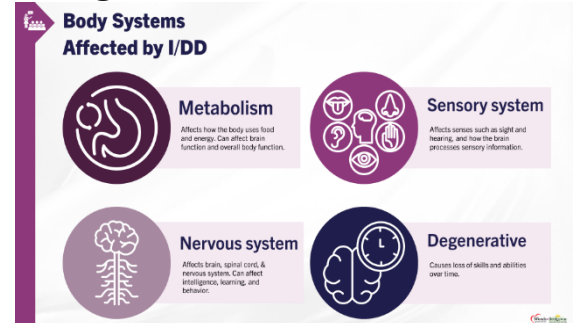
Sensory System: Conditions that affect the senses, like sight and hearing, or how the brain processes sensory information.

Degenerative Disorders: Conditions that cause a loss of skills and abilities over time, often not detected until later in life.

Both ID and DD mean that an individual often needs significant support in daily activities in order to function.

(NIH-Office of Communications, 2021)

Timing: 1 min



Do:

Definitions appear on click

Material Notes:

Trainer Notes:

16 I/DD DIAGNOSIS

Facilitator's Notes

Speaker Script:

Diagnosing I/DD is a multi-step process that involves comprehensive assessments. There are three key criteria that must be met before a diagnosis is given:

An individual must have:

1. **Limitations in intellectual functioning**, typically reflected by an IQ score that is 2 standard deviations below the mean.
2. **Limitations in adaptive behavior**, 2 standard deviations below the mean in one or more of the following areas: conceptual, social, or practical skills that are also 2 standard deviations below the mean.
3. **Both of these limitations must be present before the age of 22**, or the end of the Childhood/Adolescence Developmental Period. (Balasundaram, 2023)

There is some debate about the age of 18 or 22, and various reasons for those ages to be used as benchmarks, but appearance and diagnosis before the age of 22 is appropriate for this training. In the DSM-5, there has been a de-emphasis on the IQ score in diagnosing I/DD, and a greater emphasis on the individual's adaptive functioning. This can give a fuller picture of the individual's strengths and weakness versus just an IQ score.

One thing to note is that there might be multiple diagnoses, and not all of them might be current or up to date. Depending on the complexity of conditions an individual has, they might have a list of diagnoses from various providers that have never been resolved or removed when no longer relevant. Even if you aren't diagnosing, it is important to see for yourself the behaviors and challenges when making an assessment.
(AAIDD, 2021) (Balasundaram, 2023)

Trainer Notes:

Timing: 2 min

I/DD Diagnosis

- 1 Limitation in Intellectual Functioning**
IQ score 2 standard deviations below the mean
- 2 Limitation in Adaptive Behavior**
2 standard deviations below the mean in one or more of the following:
 - Conceptual Skills
 - Social Skills
 - Practical Skills
- 3 Age of Presentation**
Both limitations present before the age of 22

Classification of an ID diagnosis by mild, moderate, severe, and profound are determined by their IQ scores

Clinical Term	IQ score
Borderline	71-84
Mild	55-59 up to around 70
Moderate	35-45 up to around 50-54
Severe	20-25 up to around 30-34
Profound	below 20-25

Do:

On click appears a classification of ID by IQ scores

Material Notes:

17 SHIFT IN THINKING

Facilitator's Notes

Speaker Script:

In the DSM-5, there has been a shift in thinking to place a greater importance on adaptive behaviors rather than IQ scores when diagnosing an individual.

There is an emphasis on looking at a person's **conceptual skills**, and how well they are at:

- Reading, writing, and language
- Telling time
- Handling money
- Executive functioning (planning, strategizing, and setting priorities)
- Memory

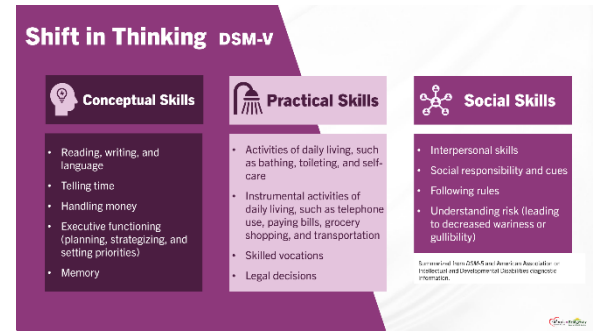
Practical skills considered are:

- Activities of daily living, such as bathing, toileting, and self-care
- Instrumental activities of daily living, such as telephone use, paying bills, grocery shopping, and transportation
- Skilled vocations
- Legal decisions

Social skills such as:

- Interpersonal skills
- Social responsibility and cues
- Following rules
- Understanding risk (leading to decreased wariness or gullibility)

Timing: 1 min



Do:

Material Notes:

Trainer Notes:

18 IMPORTANCE OF DIAGNOSIS

Facilitator's Notes

Speaker Script:

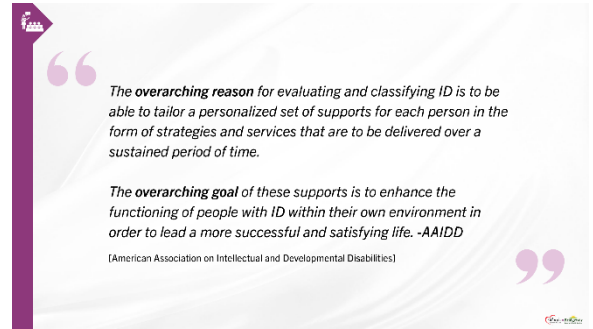
Why is it important to accurately diagnose Intellectual and Developmental Disabilities? The primary reason is to develop a personalized support plan that helps individuals lead successful and satisfying lives. By understanding the specific needs and strengths of each person, we can tailor strategies and services that will support their full participation in the community.

(AAIDD, 2021) [American Association on Intellectual and Developmental Disabilities]

When you begin to work with Individuals with I/DD, you also become a member of their support team and will be part of creating that support plan to help an individual realize their goals. Their I/DD diagnosis can have a big effect on their Mental Health and working to address Mental Health concerns in the context of their I/DD will increase the success of therapy.

Trainer Notes:

Timing: 1 min



Do:

Material Notes:

19 PREVALENCE OF I/DD

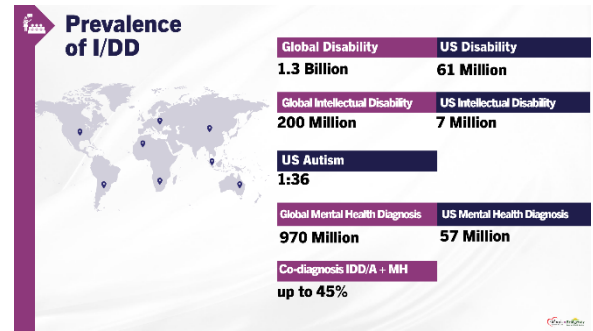
Facilitator's Notes

Speaker Script:

It's important to understand how many people are affected by I/DD and Mental Health issues around the world. In the United States, 61 million people live with a disability, with 1.3 billion affected globally. Over 7 million Americans have an intellectual disability, and 200 million people worldwide are affected. Autism diagnoses are on the rise, now at 1 in 36 in the U.S. Additionally, 57 million Americans have a mental health diagnosis. A significant portion of individuals with I/DD or autism, around 30-40%, have a co-occurring mental health condition, making them a very complex population to support.

(Lauer & McCallion, 2015) (Murphy, Xu, Kochanek, Curtin, & Arias, 2017) (National Association of State Mental Health Program Directors Council, 2006) (World Health Organization)

Timing: 1 min



Do:

Material Notes:

Trainer Notes:

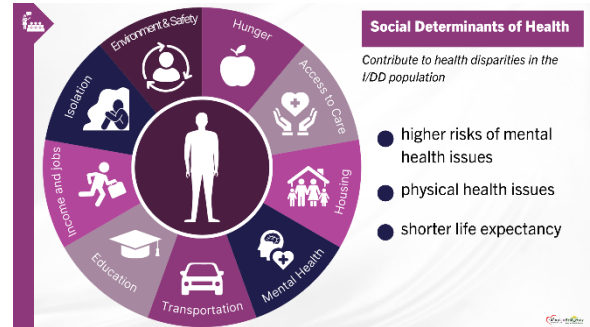
20 SOCIAL DETERMINANTS OF HEALTH

Facilitator's Notes

Speaker Script:

Social determinants of health, such as access to care, housing, income, education, and transportation, play a significant role in the health outcomes of all individuals, but especially in individuals with I/DD due to the complexities of the challenges they face. These factors can contribute to health disparities, such as higher risks of mental and physical health issues and shorter life expectancy. Addressing these disparities requires a comprehensive approach that considers both the social and medical needs of this population.

Timing: .5 min



Do:

Bullet Points appear on click

Material Notes:

21

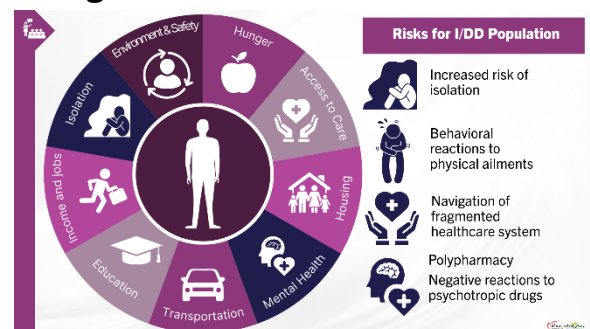
Facilitator's Notes

Speaker Script:

The results of those health disparities mean that on average, people with I/DD die 15.8 years younger, and people with serious mental illness, regardless of if they have a co-occurring I/DD diagnosis, die on average 25 years younger. When working with individuals with a co-diagnosis of I/DD and Mental Illness, it is important to consider some of the different risk factors they face. We will cover these in greater depth throughout the five courses, but they include:

- increased risk of isolation
- minor physical ailments causing intense behavioral reactions
- trouble navigating the fragmented health care system
- a risk of poly-pharmacy, and/or negative reactions to psychotropic drugs (Taylor, et al., 2015)

Timing: 1 min



Do:

Stats disappear with click and Icon Points appear on click

Material Notes:

Trainer Notes:

22 INTERDISCIPLINARY TEAM

Facilitator's Notes

Speaker Script:

As we go through these 5 Sections, we will speak about the Support Team and the Interdisciplinary Team. These two terms will be used in slightly different capacities.

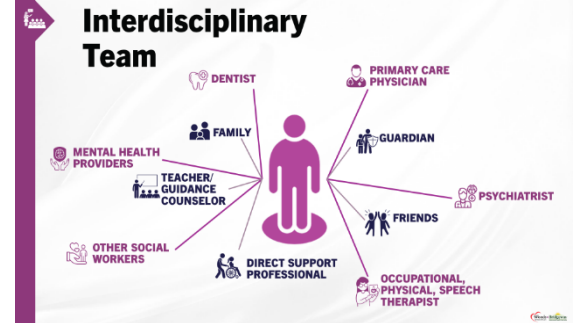
The Interdisciplinary Team encompasses all the people that provide care, support, or intervention to the Individual, both clinicians and non-clinicians. The people on this team are the ones that write and create the support plan for the individual and implement the plans.

When the Support Team is referred to, this is a specific reference to the people that provide direct support to an individual on a day-to-day basis. This might be a Direct Support Professional, a family member, a guardian, or even a teacher or guidance counselor. They are also considered part of the Interdisciplinary Team, but they are often the ones implementing the plans written by the clinicians. They have special insight into the individual and their strengths and weaknesses, as well as their needs and struggles.

As you join their Interdisciplinary Team, it is important to consider how these determinants of health might be affecting both the physical and mental health of the individual. Working with them to overcome struggles and achieve goals can go a long way in helping them overcome the gaps in their determinants of health.

Trainer Notes:

Timing: 1 min



Do:

First Click: IDT appears

Second Click: Support Team appears

Material Notes:

The Support Team is technically included as part of the IDT. However, for the purpose of this training we have separated them to provide clarity between the professional clinicians who have limited contact with the individual, and the people that provide day-to-day support.

23 IMPACT OF I/DD

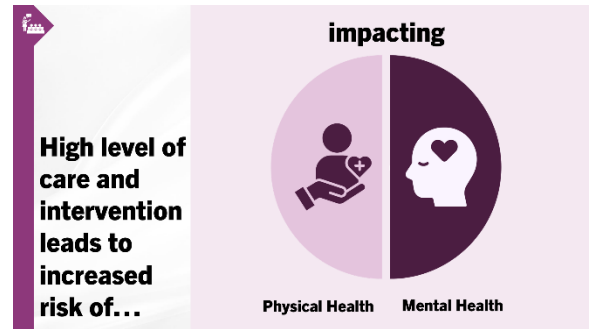
Facilitator's Notes

Speaker Script:

Both Developmental and Intellectual Disabilities contribute to a higher level of care and intervention needs. Individuals with I/DD are at greater risk for trauma, abuse, and other factors that can negatively affect both their mental and physical health. This is why it's crucial to ensure they receive timely and appropriate care.

Individuals with I/DD need a tailored approach and specific supports in daily living skills for them to reach their full potential. Just as you tailor a treatment plan for all the people you work with, your work with an individual with I/DD will also need to be specifically tailored and take into account their I/DD diagnosis. (Houck & Dracobly, 2022)

Timing: .5 min



Do:

Purple box appears on click

Material Notes:

24 COMMON DIAGNOSES

Facilitator's Notes

Speaker Script:

There are many different syndromes and disorders that fall into the I/DD category. While we can't go into the specifics too much during today's training, we will touch on a few of the more common diagnoses that you might see in your practice. Additional information on these diagnoses can be found in the handout.

Timing: .5 min



Do:

Material Notes:

Trainer Notes:

Facilitator's Notes

Speaker Script:

Autism is a neurodevelopmental disorder characterized by impairments in social interaction and communication, along with repetitive or stereotyped patterns of behaviors and often restricted interests.

It was first described in 1943 but wasn't officially recognized until DSM-III in 1980. In 2013, DSM-5 introduced the term Autism Spectrum Disorder, and other sub-categories were eliminated.

Because it is a spectrum disorder, presentation and severity can vary widely. To be diagnosed, an individual must meet criteria in each of the following four areas:

4 criteria to be met

- A** - Social Communication and Interactions
- B** - Restricted, Repetitive Behavior
- C** - Early Childhood Symptoms
- D** - Limit or impair everyday functioning

Stats:

- In the US, 1 in 36 are diagnosed with Autism at a ratio of 4 to 1 boys to girls.
- Approximately 25-35% of children with ASD are minimally-verbal. (Rose, Trembath, Keen, & Paynter, 2016)
- 31% of children with ASD have an intellectual disability, and 25% are in the borderline range of intellectual disability.
- Almost 50% have a tendency to wander or bolt.
- Approximately a quarter of the children with ASD have self-injurious behaviors such as head banging, arm biting, or skin scratching.

[a note on all statistics, these disorders and conditions are constantly being studied and understood in different lenses. These statistics will change often.]

Timing: 2 min

Do:

First Click: Stats appear

Material Notes:

The following slides are for informational purposes. They can be used or skipped as you want.

Autism doesn't fit into any bucket completely. It's included in the DSM-5 as a mental health condition, but it doesn't really fit there fully. It's also not completely an intellectual disability. It's important to stay up to date on new studies and research that give a more complete picture of Autism.

Another thing to be aware of is the rise in adult diagnoses of Autism or even adults self-diagnosing with Autism. These individuals have often been able to overcome difficulties on their own but might still have significant impacts on their life due to having an Autism diagnosis.

Trainer Notes:

26 AUTISM

Facilitator's Notes

Speaker Script:

Common Presentations of ASD are:

- avoiding eye contact
- appearing to be unaware when people talk
- having trouble understanding feelings or trouble expressing their needs
- repeating actions over and over again
- Having strong reactions to the way things smell, taste, look, feel, or sound
- SIB, property destruction, aggression

Potential Challenges that might be faced in the clinical setting are:

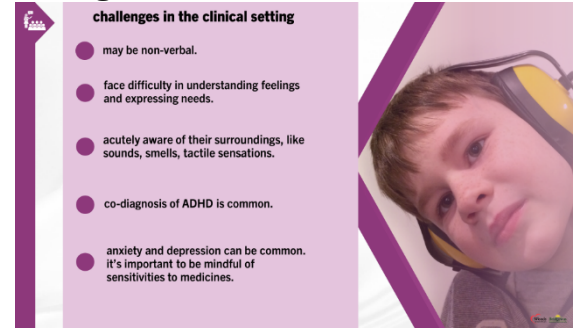
- non-verbal
- difficulty in understanding feelings
- difficulty in expressing needs
- Acutely aware of surroundings (i.e. in an office, sounds, smells, tactile etc.)
- Often have a co-diagnosis of ADHD
- Anxiety and Depression can be common

It is important to be mindful of reactions and sensitivities to medicines.

(American Psychiatric Association, 2013) (Chahin, Apple, Kuo, & Dickson, 2020) (Lord, et al., 1989) (Ozonoff, Goodlin-Jones, & Solomon, 2005) (Siu, et al., 2016)

Trainer Notes:

Timing: 1 min



challenges in the clinical setting

- may be non-verbal.
- face difficulty in understanding feelings and expressing needs.
- acutely aware of their surroundings, like sounds, smells, tactile sensations.
- co-diagnosis of ADHD is common.
- anxiety and depression can be common. It's important to be mindful of sensitivities to medicines.

Do:

First Click: Challenges in the Clinical Setting appears

Material Notes:

The following slides are for informational purposes. They can be used or skipped as you want.

27 DOWN SYNDROME

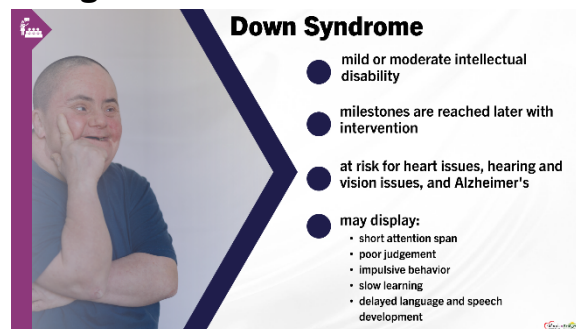
Facilitator's Notes

Speaker Script:

Down Syndrome is the result of an extra copy or a part of an extra copy of chromosome 21. It is diagnosed either through prenatal testing or physical symptoms at birth.

Individuals with Down Syndrome usually have a mild or moderate Intellectual Disability. They can typically reach milestones, but later than other children and often with intervention. They have an increased risk for heart and vision issues and for developing Alzheimer's. With support and treatment, they lead happy and productive lives. Some of the Cognitive and Behavioral presentations might be a short attention span, poor judgement, impulsive behavior, slow learning, and delayed language and speech development.

Timing: 1 min



Down Syndrome

- mild or moderate intellectual disability
- milestones are reached later with intervention
- at risk for heart issues, hearing and vision issues, and Alzheimer's
- may display:
 - short attention span
 - poor judgement
 - impulsive behavior
 - slow learning
 - delayed language and speech development

Do:

Material Notes:

28

Facilitator's Notes

Speaker Script:

Statistics:

- Life expectancy has increased from 25 years in 1983 to 60 years today –

This is mainly because of better diagnoses, treatments, and interventions that occur at an earlier age. They are also no longer institutionalized, and they are more fully integrated into the community.

- 6,000 babies are born with Down Syndrome each year in the US.
- 50% will experience a major mental health concern during their lifetime (same as general population).

Timing: 1 min



Statistics:

- life expectancy has increased from 25 years in 1983 to 60 years today
- 6,000 babies are born with Down Syndrome each year in the US
- 50% will experience a major mental health concern during their lifetime (same as general population)

Potential Challenges in the Clinical Setting:

- communication challenges
- hearing and sight difficulties are common
- rule out physical issues presenting as MH issues (in conjunction with PCP)

Do:

Material Notes:

Potential Challenges in the Behavior and Mental Health

Setting:

- Communication challenges
- Hearing and sight difficulties are common
- Rule out physical issues (in conjunction with PCP)

(National Institute of Health, 2023) (National Down Syndrome Society, 2024) (Global Down Syndrome Foundation, n.d.)

Trainer Notes:

29 CEREBRAL PALSY

Facilitator's Notes

Speaker Script:

Cerebral Palsy is a group of brain disorders that primarily affect body movement and muscle coordination. It's caused by damage to the part of the brain responsible for controlling these functions. Importantly, Cerebral Palsy is not a progressive condition; it doesn't worsen over time, but it is permanent and lasts throughout the individual's life.

Cerebral Palsy is usually diagnosed in infancy or early childhood, often during routine well-baby or well-child visits. If a healthcare provider suspects Cerebral Palsy, a brain scan can confirm the diagnosis. Early diagnosis is crucial for managing the symptoms and planning for the necessary interventions.

(National Institute of Health, 2021) (Hallman-Cooper & Cabrero, 2024) (Green, 2018)

Trainer Notes:

Timing: .5 min



Cerebral Palsy

- most common body movement disorder
- caused by damage to the brain
- not progressive, but lasts the whole life
- typically diagnosed in infancy or early childhood.

Do:

Material Notes:

The following slides are for informational purposes. They can be used or skipped as you want.

30 CEREBRAL PALSY

Facilitator's Notes

Speaker Script:

Cerebral Palsy presents with a wide range of symptoms and can vary significantly in severity from one individual to another. Some individuals with CP may require intensive physical support and lifelong care, while others may need only minimal assistance.


There are different types of Cerebral Palsy, with some being more commonly associated with Intellectual and Developmental Disabilities than others. The presentations can include:

- Spastic movements and uncontrolled muscle actions.
- Difficulty with speech and language, including conditions like Ataxia, which is a loss of muscle coordination, and Spasticity, characterized by stiff or tight muscles and jerky movements.
- Muscle tone abnormalities, either too stiff or too floppy.
- Challenges with walking, such as walking on the toes or in a crouched position.
- Issues with precise movements, like writing or buttoning a shirt.
- In infants and toddlers, delays in reaching motor milestones such as sitting, crawling, or walking.

Cerebral Palsy is the most common movement disorder in children, affecting about 1.5 to 2.5 per 1,000 live births. It is more prevalent in pre-term births, with prenatal events accounting for 80% of cases and post-natal events for 10%.

In a behavioral and mental health setting, individuals with Cerebral Palsy are at an increased risk for anxiety and depression, making it essential to provide comprehensive care that addresses both their physical and mental health needs.

Timing: 2 min



Stats

- affects 1.5-2.5 per 1,000 live births
- prenatal events account for 80% of cases
- postnatal events account for 10%
- certain types are at higher risk for intellectual disabilities

Challenges

- increased risk for anxiety and depression
- speech difficulties might mean they need to use a communication device

National Institute of Health, 2021 (Heldman-Cooper & Cabero, 2024) (Green, 2020)

Do:

First Click: Challenges in the Clinical Setting appears

Material Notes:

The following slides are for informational purposes. They can be used or skipped as you want.

They might have difficulties with speech and use a communication device. Typically, with a communication device, even non-verbal C.P. patients can communicate effectively.

Trainer Notes:

31 FETAL ALCOHOL SPECTRUM DISORDER

Facilitator's Notes

Speaker Script:

Fetal Alcohol Spectrum Disorder, or FASD, is a serious condition that results from alcohol exposure during pregnancy. This exposure interferes with the development of the brain and other critical organs in the fetus. FASD is often underdiagnosed or misdiagnosed because its symptoms can resemble those of other developmental disorders.

Healthcare providers typically look for several key indicators when diagnosing FASD:

Prenatal Alcohol Exposure: While confirmation of alcohol exposure isn't always required for diagnosis, it is an important factor.

Central Nervous System Problems: This can include small head size, issues with attention and hyperactivity, and poor coordination.

Lower-than-Average Height and Weight: Children with FASD often have growth deficits.

Abnormal Facial Features: One common sign is a smooth ridge between the nose and upper lip.

There's also a specific neurobehavioral disorder associated with prenatal alcohol exposure, known as **ND-PAE**, which is recognized in the **DSM-5**. Children with **ND-PAE** may struggle with memory, behavior, and day-to-day living tasks. It's important to note that for a diagnosis of **ND-PAE**, there must be a history of significant alcohol consumption by the mother during pregnancy.

(Clarke & Gibbard, 2003) (CDC, n.d.) (National Institute of Health, n.d.)

Timing: 1.5 min



Do:

Material Notes:

The following slides are for informational purposes. They can be used or skipped as you want.

Trainer Notes:

32 FASD

Facilitator's Notes

Speaker Script:

Fetal Alcohol Spectrum Disorder presents with a range of physical, behavioral, and cognitive impairments that can create significant challenges, especially in clinical and behavioral health settings. Individuals with FASD may experience difficulties with:

Learning and Memory: Challenges in retaining information and following directions.

Attention and Task Management: Difficulty switching attention between tasks and controlling impulses.

Emotional and Social Skills: Struggles with controlling emotions, developing social skills, and communicating effectively.

Daily Life Skills: Problems performing basic tasks like feeding, bathing, managing money, and maintaining personal safety.

Statistics show that FASD affects about 1-5% of children in the first grade. Alarmingly, nearly 10% of pregnant women report current alcohol use, with binge drinking rates also concerningly high, especially in the first trimester.

In a behavioral health setting, it's crucial to be aware of the potential for significant mental health issues among individuals with FASD, including depression, anxiety, suicidal ideation, impulse control issues, and substance abuse. Other challenges may include aggression, withdrawal, and impulsive behaviors, all of which require careful management and support.

As a side note, FASD is directly caused by substance abuse by the mother. For more severe cases, there must be documented alcohol abuse by the mother during prenatal development. If you work with individuals with alcohol problems who are pregnant or may become pregnant, this is an issue to be aware of and discuss with the individual.

Trainer Notes:

Timing: 1 min



Stats

- affects 1-5% of 1st grade children
- nearly 10% of pregnant women report drinking alcohol
- affects
 - Learning and Memory
 - Attention and Task Management
 - Emotional and Social Skills
 - Daily Life Skills

Challenges

- increased risk for anxiety and depression
- suicidal ideation
- impulse control issues
- high risk for substance abuse

Do:

Material Notes:

The following slides are for informational purposes. They can be used or skipped as you want.

33 TOURETTE SYNDROME & NEURODIVERGENCE

Facilitator's Notes

Speaker Script:

Tourette Syndrome is a part of the broader concept of neurodivergence. Neurodivergence refers to a range of neurodevelopmental disorders that typically become apparent in childhood, and Tourette Syndrome is one of these conditions. Individuals with ADHD and Autism also often refer to themselves as neurodivergent. Tourette's is part of the spectrum of tic disorders, which can sometimes be transient.

Timing: .5 min



Do:

Material Notes:

The following slides are for informational purposes. They can be used or skipped as you want.

Trainer Notes:

34 TOURETTE SYNDROME & NEURODIVERGENCE

Facilitator's Notes

Speaker Script:

Tourette Syndrome, also known as Tourette's Disorder, is diagnosed based on several criteria:

1. **Motor and Vocal Tics:** The presence of at least two motor tics and one vocal (phonic) tic, though they don't have to occur simultaneously.
2. **Duration:** The tics may wax and wane in frequency but must have been present for more than one year.
3. **Onset:** Tics must have started before the age of 18.
4. **Exclusion of Other Causes:** The tics are not caused by substance use or another medical condition.

In addition to Tourette Syndrome, other related tic disorders include:

Persistent (Chronic) Motor or Vocal Tic Disorder:

Characterized by either motor tics or vocal tics lasting more than one year, but not both.

Provisional Tic Disorder: Involves motor and/or vocal tics that have been present for less than one year and do not meet the criteria for more chronic tic disorders.

(Tourette Association of America, n.d.) (Tourette Association of America, n.d.) (Mayo Clinic, n.d.) (Baumer & Frueh, 2021)

Timing: 1 min



Do:

Material Notes:

The following slides are for informational purposes. They can be used or skipped as you want.

Trainer Notes:

35 TOURETTE SYNDROME & NEURODIVERGENCE

Facilitator's Notes

Speaker Script:

Tourette Syndrome often co-occurs with other conditions such as ADHD and OCD, which can complicate both diagnosis and treatment. The primary symptoms of Tourette Syndrome are motor and vocal/phonic tics. These can range in severity and may impact daily functioning.

Statistics show that approximately 1 in 160 children have Tourette Syndrome, and about 1 in 5 school-aged children may experience tics that could be part of a transient tic disorder. Males are 3 to 4 times more likely to have Tourette Syndrome than females. While tics often fade into adulthood, there's no clear data on how many adults are affected by Tourette Syndrome.

In a behavioral and mental health setting, individuals with Tourette Syndrome may face several challenges, including:

ADHD: Problems with concentration, hyperactivity, and impulse control.

OCD/OCB: Repetitive, unwanted thoughts and behaviors that the individual feels compelled to perform.

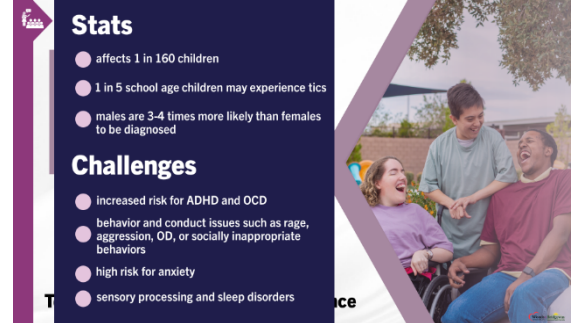
Behavioral or Conduct Issues: These can include aggression, rage, oppositional defiance, or socially inappropriate behaviors.

Anxiety: Excessive worries, fearfulness, and sometimes social anxiety or separation anxiety.

Learning Disabilities: Difficulties with reading, writing, mathematics, or processing information that are not related to intelligence.

Social Skills Deficits: Trouble developing and maintaining social relationships and acting in an age-appropriate manner.

Timing: 1 min



Stats

- affects 1 in 160 children
- 1 in 5 school age children may experience tics
- males are 3-4 times more likely than females to be diagnosed

Challenges

- increased risk for ADHD and OCD
- behavior and conduct issues such as rage, aggression, OD, or socially inappropriate behaviors
- high risk for anxiety
- sensory processing and sleep disorders

The infographic also features a photograph of three young people (two men and one woman) sitting outdoors and laughing joyfully.

Do:

Material Notes:

The following slides are for informational purposes. They can be used or skipped as you want.

Sensory Processing Issues: Strong preferences and sensitivities to sensory stimuli, such as touch, sound, taste, smells, and movement.

Sleep Disorders: Challenges with falling or staying asleep.

Trainer Notes:

36 OTHER COMMON DIAGNOSES

Facilitator's Notes

Speaker Script:

Some other common diagnoses of I/DD are Fragile X, Prader-Willi, and Traumatic Brain Injuries. These diagnoses are less prevalent in the population and can often involve significant challenges and limitations for the individual.

Timing: .5 min



Do:

Material Notes:

Trainer Notes:

37 NON-APPARENT DISABILITIES

Facilitator's Notes

Speaker Script:

Sometimes a disability isn't apparent. "Non-apparent disabilities" is the term that has risen to describe these, and often it is used to describe people with mental health issues that you might not see at first. For example, an individual with OCD that is functioning well, or a cancer survivor who looks fine, but still occasionally needs physical supports.

In this training, we are using this term to refer to individuals with I/DD who might only have mild intellectual impairment, individuals who never received a proper diagnosis when they were children for a variety of reasons, or individuals who have self-diagnosed themselves with something like ASD or Tourette or another neurodiverse symptom. When first meeting with an individual like this, they may not appear any different, but they still have processing issues and other barriers to communication that are important to consider when communicating with them. Some things to consider are:

Sensitivity - to the individual and providing clear communication for them to process.

Space for revealing - they may or may not want to talk about it.

Respect for the individual - remembering that they are people above all and what they want most is the same as everyone: a recognition that they matter and are seen.

Encouragement for clinical diagnosis - if a lack of diagnosis is hindering them in their treatment plan and general life, it might be appropriate to encourage them to seek more in-depth help.

Timing: 1.5 min



Do:

Material Notes:

Trainer Notes:

38 DEVELOPMENTAL CONSIDERATIONS

Facilitator's Notes

Speaker Script:

When working with an individual with I/DD, it's important to remember that their diagnosis impacts their development. Their chronological age likely won't match their developmental age. For example, a 25-year-old might behave and communicate like a 10-year-old in terms of developmental and cognitive functioning.

Their diagnosis may have also led to a more isolated life with fewer social interactions. As a result, they might lack the social skills typically expected for their chronological age.

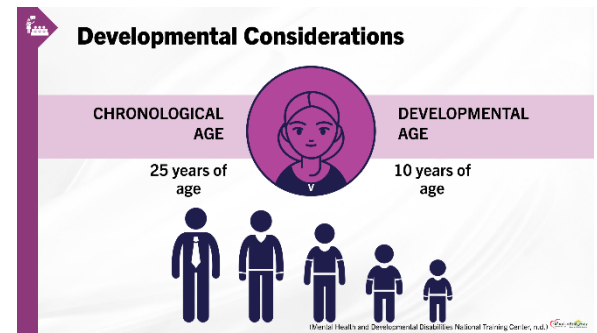
Even if their developmental age doesn't match their chronological age, it is important to treat them according to their actual age. Infantilizing them doesn't help them to reach their full potential, nor does it consider the full range of experiences they have had throughout their life.

As a clinician, you probably won't initially know their developmental age. However, with attention and awareness, you'll be able to understand how to meet them where they are. Due to their diagnosis, they may need more support for communication and understanding than someone without an I/DD diagnosis, but it doesn't mean that they aren't adults with hopes and dreams of their own.

Throughout these courses, we'll provide tips and techniques to improve your ability to assess and support these individuals at their developmental level.

(Mental Health and Developmental Disabilities National Training Center, n.d.)

Timing: 1.5 min



Do:

Material Notes:

Trainer Notes:

39 QUOTE

Facilitator's Notes

Speaker Script:

The human spirit is one of ability, perseverance and courage, that no disability can steal away."

Unknown

(Cleveland Clinic, 2021)

Timing: 1 min



Do:

Material Notes:

Trainer Notes:

40 CLOSING VIDEO

Facilitator's Notes

Speaker Script:

This is a nice video and could be a good way to end the section or the training session as a whole

<https://www.youtube.com/watch?v=eGfG7J3ibdI>

(Cleveland Clinic, 2021)

Timing: 1 min



Do:

Material Notes:

Trainer Notes:

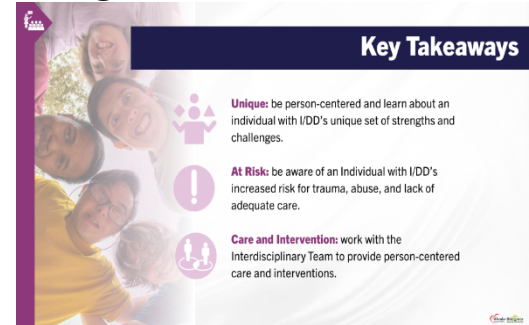
41 KEY TAKEAWAYS

Facilitator's Notes

Speaker Script:

- Unique: be person-centered and learn about an individual with I/DD's unique set of strengths and challenges.
- At Risk: be aware of an Individual with I/DD's increased risk for trauma, abuse, and lack of adequate care
- Care and Intervention: work with the Interdisciplinary Team to provide person-centered care and interventions.

Timing: 1 min



Do:

Material Notes:

Trainer Notes:

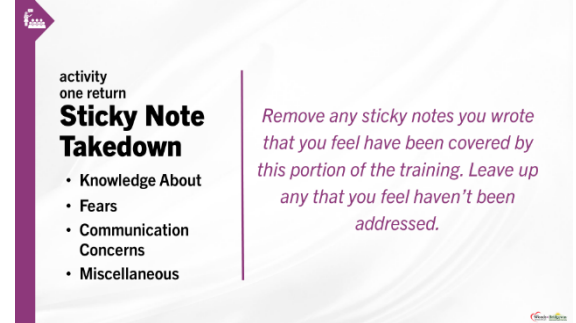
42 ACTIVITY: STICKY NOTES

Facilitator's Notes

Speaker Script:

Before our break, we are going to re-visit our sticky notes. At this point, go and remove any sticky note you wrote that you now feel has been answered. If you would like to add anything to a sticky note, you may do that as well.

Timing: 3 min



Do:

Instruct participants to remove or add sticky notes as they feel led to.

Material Notes:

Trainer Notes:

43 REFLECTION ACTIVITY: SOMETHING

Facilitator's Notes

Speaker Script:

During the break, take a moment to write down something that you want to remember, that you want to share, and that you were surprised by.

Timing: 3 min



Do:

Participants can use reflection sheet provided.

Material Notes:

Trainer Notes:

Activities

Activity 1: Sticky Note Brainstorm

There are two different ways this activity could be included in the training session. The first way would be for it to be self-led as participants come into the training room. The slide can be up on the projector, and they can start adding their thoughts to the categories. The second way would be instructor-led after the training has begun. This would allow for more explanation if the trainer feels that might be helpful. There are slide options for both.

Instructions:

1. Before the training, have enough sticky note pads for each participant, plus pens.
2. Pass out sticky note pads to participants
3. Instruct the participants that they should brainstorm questions, thoughts, concerns, etc. regarding working and interacting with Individuals with Intellectual and Developmental Disabilities.
 - Reassure them that this is a safe space, and their names aren't going on the sticky notes.
4. They can brainstorm according to these categories:
 - What they know about Individuals with I/DD or implicit biases many people hold about them.
 - Fears they have surrounding interacting with and providing services to Individuals with I/DD
 - Concerns they have with Communication
 - Miscellaneous
5. Then, they should put their sticky notes on the wall.
6. Share that, over the course of this training, you hope that these questions and concerns will be addressed, and that the notes will be re-addressed throughout the training.

Slide 1: For a self-led exercise before the training begins.

welcome!!

Sticky Note Brainstorm

Using the categories below, write your questions, thoughts, or concerns regarding working with Individuals with I/DD on the sticky notes provided and stick them on the wall.

Knowledge about	Communication Concerns

Fears	Miscellaneous

- You do not need to write your name.
- We will refer back to these throughout the training session.
- Nothing is too basic to write down!
- The things you write down will also help us as trainers continue to develop meaningful material.

Woods x Bridgeway
Supporting People's Potential

Slide 2: For instructor led activity after the training has begun.

activity one

Sticky Note Brainstorm

- Knowledge about
- Fears
- Communication Concerns
- Miscellaneous

Using the categories above, write your questions, thoughts, or concerns regarding working with Individuals with I/DD and stick them on the wall

Woods x Bridgeway
Supporting People's Potential

Activity 1 Return: Sticky Note Takedown

Instructions:

Instruct participants to review the sticky notes they wrote and remove any that have been answered by the first session.

They should leave any that have not been answered to be reviewed after subsequent sessions.

Activity 2: Reflection

Instructions:

This is an optional closing/transitional reflection activity that can be done during a break between sessions.

In the participant guide, there is a page for answering these questions:

- Something that you want to remember
- Something that you want to share
- Something that you were surprised by

Additional Slides: XX DIFFERENCES BETWEEN DD & ID

Facilitator's Notes

Speaker Script:

Let's take a closer look at the difference between Developmental Disabilities and Intellectual Disabilities.

Developmental Disabilities include both physical and intellectual challenges. It can be seen as the broader term that also encompasses Intellectual Disabilities.

- Umbrella term for all diagnoses that happen during the developmental stage
- Lifelong impact
- Include both physical and intellectual limitations
- Appear before the age of 22

XX

Facilitator's Notes

Speaker Script:

Intellectual Disabilities, on the other hand, are a subcategory that specifically affects intellectual functioning and abilities.

- Affects intellectual functioning
- Typically diagnosed before the age of 18, but always before the age of 22
- Lifelong impact

Trainer Notes:

Timing: .5 min



Do:

Bullet points appear on click

Material Notes:

If you would rather show a video on the differences, skip to Slide 10

Timing: .5 min



Do:

Bullet points appear on click

Material Notes:

XX DIFFERENCES BETWEEN DD & ID

Facilitator's Notes

Speaker Script:

In both ID and DD, these disabilities appear before the age of 22 (18 for ID), during the developmental period, and have a lifelong impact on:

- learning,
- reasoning,
- communication,
- socialization,
- self-care.

Slides 6-10 Developed from
(AAIDD, 2021) (Psych Hub, 2021)

Timing: .5 min



Do:

Bullet points appear on click

Material Notes:

Trainer Notes:

References

- AAIDD. (2021). *FAQs on intellectual disability*. Retrieved 10 1, 2024, from American Association on Intellectual and Developmental Disabilities: <https://www.aaidd.org/intellectual-disability/faqs-on-intellectual-disability>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (Vol. 5). Washington, DC.
- Autism Speaks. (n.d.). *Autism statistics and facts*. Retrieved October 15, 2024, from Autism Speaks: <https://www.autismspeaks.org/autism-statistics-asd>
- Balasundaram, P. &. (2023). *Human Growth and Development*. Treasure Island, FL: StatPearls Publishing. Retrieved 10 1, 2024, from <https://www.ncbi.nlm.nih.gov/books/NBK567767/>
- Baumer, N., & Frueh, J. (2021, November 23). *What is neurodiversity?* Retrieved October 15, 2024, from Harvard Health Publishing: <https://www.health.harvard.edu/blog/what-is-neurodiversity-202111232645>
- CDC. (n.d.). *About Fetal Alcohol Spectrum Disorders (FASDs)*. Retrieved October 15, 2024, from CDC: Fetal Alcohol Spectrum Disorders (FASDs): <https://www.cdc.gov/fasd/about/index.html>
- Chahin, S. S., Apple, R. W., Kuo, K. H., & Dickson, C. (2020). Autism spectrum disorder: Psychological and functional assessment, and behavioral treatment approaches. *Translational pediatrics*, 9(Suppl 1), S66.
- Clarke, M. E., & Gibbard, W. B. (2003). Overview of Fetal Alcohol Spectrum Disorders for Mental Health Professionals. *The Canadian child and adolescent psychiatry review = La revue canadienne de psychiatrie de l'enfant et de l'adolescent*, 12(3), 57-63. Retrieved from NIH: National Library of Medicine.
- Cleveland Clinic. (2021, June 25). *Building Bridges: Interacting with Adults Who Have Developmental Disabilities*. Retrieved October 15, 2024, from YouTube: <https://www.youtube.com/watch?v=eGfG7J3ibdI>
- Committee to Evaluate the Supplemental Security Income Disability Program for Children with Mental Disorders; Board on the Health of Select Populations; Board on Children, Youth, and Families; Institute of Medicine; Division of Behavioral and Social Sciences and Education; The National Academies of Sciences, Engineering, and Medicine; Boat TF, Wu JT, editors. *Mental Disorders and Disabilities Among Low-Income Children*. Washington (DC): National Academies Press (US); 2015 Oct 28. 8, Clinical Characteristics of Autism Spectrum Disorder. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK332891/>
- Community Based Care, IDD Supports. (2024, September). *What is the Difference Between Intellectual and Developmental Disabilities?* Retrieved from CBC IDD Supports: <https://cbcidd.com/what-is-the-difference-between-intellectual-and-developmental-disabilities/>
- Global Down Syndrome Foundation. (n.d.). *Facts and FAQ About Down Syndrome*. Retrieved October 15, 2024, from Global Down Syndrome Foundation: <https://www.globaldownsyndrome.org/about-down-syndrome/facts-about-down-syndrome/#:~:text=in%20the%20U.S.%3F-,1.,institutionalizing%20people%20with%20Down%20syndrome>
- Green, A. (2018). *Cerebral Palsy and Mental Health*. Retrieved from CanChild: <https://www.canchild.ca/en/resources/297-cerebral-palsy-and-mental-health>
- Hallman-Cooper, J. L., & Cabrero, F. R. (2024, February 24). *Cerebral Palsy*. Retrieved from NIH: National Library of Medicine: <https://www.ncbi.nlm.nih.gov/books/NBK538147/#:~:text=Cerebral%20palsy%20is%20the%20most,2.5%20per%201000%20live%20births>
- Ho, A. Y., & Dimitropoulos, A. (2010). Clinical management of behavioral characteristics of Prader-Willi syndrome. *Neuropsychiatric disease and treatment*, 6, 107-118. doi:<https://doi.org/10.2147/ndt.s5560>
- Katy Kunst, M. Q. (2022, December 3). Crisis Intervention for Individuals with IDD. *REL-IDD-0-CIIIDD*. Relias.

- Lauer, E., & McCallion, P. (2015). Mortality of People with Intellectual and Developmental Disabilities from Select US State Disability Service Systems and Medical Claims Data. *J Appl Res Intellect Disabil*.
- Lord, C., Rutter, M., Goode, .., Heemsbergen, J., Jordan, H., Mawhood, L., & Schopler, .. (1989). Autism diagnostic observation schedule: A standardized observation of communicative and social behavior. *Journal of autism and developmental disorders*, 19(2), 185-212.
- Mayo Clinic. (n.d.). *Tourette Syndrome*. Retrieved October 15, 2024, from Mayo Clinic: <https://www.mayoclinic.org/diseases-conditions/tourette-syndrome/symptoms-causes/syc-20350465>
- Mental Health and Developmental Disabilities National Training Center. (n.d.). *MHDD: Intellectual Disability 101*. Retrieved October 15, 2024, from MHDD: [https://rise.articulate.com/share/lCZUGJvMsx4f-K7dsGHZ9yQg235h8XIU#/?](https://rise.articulate.com/share/lCZUGJvMsx4f-K7dsGHZ9yQg235h8XIU#/)
- Murphy, S., Xu, J., Kochanek, K., Curtin, S., & Arias, E. (2017, November 27). Deaths: Final Data for 2015. *CDC National Vital Statistics Reports*, 66(6).
- National Association of State Mental Health Program Directors Council. (2006). *Morbidity and Mortality in People with Serious Mental Illness*. Alexandria, VA.
- National Core Indicators. (2024, September). *In-Person Survey*. Retrieved from NCI IDD: https://idd.nationalcoreindicators.org/wp-content/uploads/2024/07/22-23_NCI-IDD_IPS_DataGlance.pdf
- National Disability Navigator Resource Collaborative. (n.d.). *Population Specific Fact Sheet – Autism Spectrum Disorder*. Retrieved October 15, 2024, from National Disability Navigator Resource Collaborative: <https://nationaldisabilitynavigator.org/ndnrc-materials/fact-sheets/population-specific-fact-sheet-autism-spectrum-disorder/>
- National Down Syndrome Society. (2024). *Mental Health and Down Syndrome*. Retrieved October 15, 2024, from National Down Syndrome Society: <https://ndss.org/resources/mental-health-down-syndrome#:~:text=The%20most%20common%20mental%20health,%2C%20depression%2C%20and%20tic%20disorder>
- National Institute of Health. (n.d.). *Understanding Fetal Alcohol Spectrum Disorders*. Retrieved October 15, 2024, from NIH: National Institute on Alcohol Abuse and Alcoholism: <https://www.niaaa.nih.gov/publications/brochures-and-fact-sheets/understanding-fetal-alcohol-spectrum-disorders>
- National Institute of Health. (2021, May 11). *Cerebral Palsy*. Retrieved from National Institute of Health: <https://www.nichd.nih.gov/health/topics/cerebral-palsy>
- National Institute of Health. (2023, November 30). *Down Syndrome Fact Sheet*. Retrieved from National Institute of Health: <https://www.nichd.nih.gov/health/topics/factsheets/downsyndrome>
- NIH. (2021, November 9). *National Institute of Health*. Retrieved from What causes intellectual and developmental disabilities (IDDs)?: <https://www.nichd.nih.gov/health/topics/idds/conditioninfo/causes>
- NIH-Office of Communications. (2021, 11 9). *About Intellectual and Developmental Disabilities (IDDs)*. Retrieved from National Institute of Health: <https://www.nichd.nih.gov/health/topics/idds/conditioninfo>
- Ozonoff, S., Goodlin-Jones, B. L., & Solomon, M. (2005). Evidence-based assessment of autism spectrum disorders in children and adolescents. *Journal of Clinical Child and Adolescent Psychology*, 34(3), 523-540.
- Pinals, D. A., Hovermale, M. D., Mauch, D., & Anacker, M. D. (2021, August 4). Persons With Intellectual and Developmental Disabilities in the Mental Health System: Part 1. Clinical Considerations. *Psychiatric Services*, 73(3). doi:<https://doi.org/10.1176/appi.ps.201900504>
- Psych Hub. (2021, October 20). *What is IDD?* Retrieved from YouTube: <https://www.youtube.com/watch?v=rymHXQmiugl>

- Siu, A. L., Bibbins-Domingo, K., Grossman, D. C., Baumann, L. C., Davidson, K. W., Ebell, M., & US Preventive Services Task Force. (2016). Screening for autism spectrum disorder in young children: US Preventive Services Task Force recommendation statement. *Jama*, 315(7), 691-696.
- Taylor, L., Coyle, C., Ndumele, E., Rogan, E., Canavan, M., Curry, L., & Bradley, E. (2015). *Leveraging the social determinants of health: what works?* Yale Global Health Leadership Institute, Prepared for the Blue Cross Blue Shield of Massachusetts Foundation. Health Management Associates.
- Tourette Association of America. (n.d.). *Tourette Syndrome: An Overview*. Retrieved October 15, 2024, from Tourette Association of America: https://tourette.org/about-tourette/overview/?gad_source=1&gclid=Cj0KCQjwllG2BhC4ARIsADBgpVRPg8dVkqzwsQw1-LSTg_a6rS3TH7GWZ7SylkGjDeeDr8EzjEmxplgaAoLbEALw_wcB
- Tourette Association of America. (n.d.). *What is Tourette*. Retrieved October 15, 2024, from Tourette Association of America: <https://tourette.org/about-tourette/overview/what-is-tourette/>
- World Health Organization. (n.d.). *Health Topics Fact Sheet on Disability*. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/disability-and-health#:~:text=An%20estimated%201.3%20billion%20people,1%20in%206%20of%20us.>
- World Health Organization. (n.d.). *Mental Disorders Fact Sheet*. Retrieved 6 13, 24, from [https://www.who.int/news-room/fact-sheets/detail/mental-disorders#:~:text=There%20are%20many%20different%20types%20of%20mental%20disorders.,the%20most%20common%20\(1\)](https://www.who.int/news-room/fact-sheets/detail/mental-disorders#:~:text=There%20are%20many%20different%20types%20of%20mental%20disorders.,the%20most%20common%20(1))
- World Health Organizations. (n.d.). *Ageing and Health Factsheet*. Retrieved 6 13, 24, from <https://www.who.int/news-room/fact-sheets/detail/ageing-and-health#:~:text=Every%20country%20in%20the%20world,in%202020%20to%201.4%20billion>

This work is supported by the New Jersey Council on Developmental Disabilities, in part by grant number 2301NJSCDD, from the U.S. Administration for Community Living (ACL), Department of Health and Human Services (HHS), Washington, D.C. 20201 as part of a financial assistance award totaling \$2,168,166.00 with 85% funded by ACL/HHS and 15% funded by the State of NJ. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.