PROVIDING EFFECTIVE THERAPY TO CLIENTS WITH AUTISM OR OTHER DEVELOPMENTAL DISABILITIES

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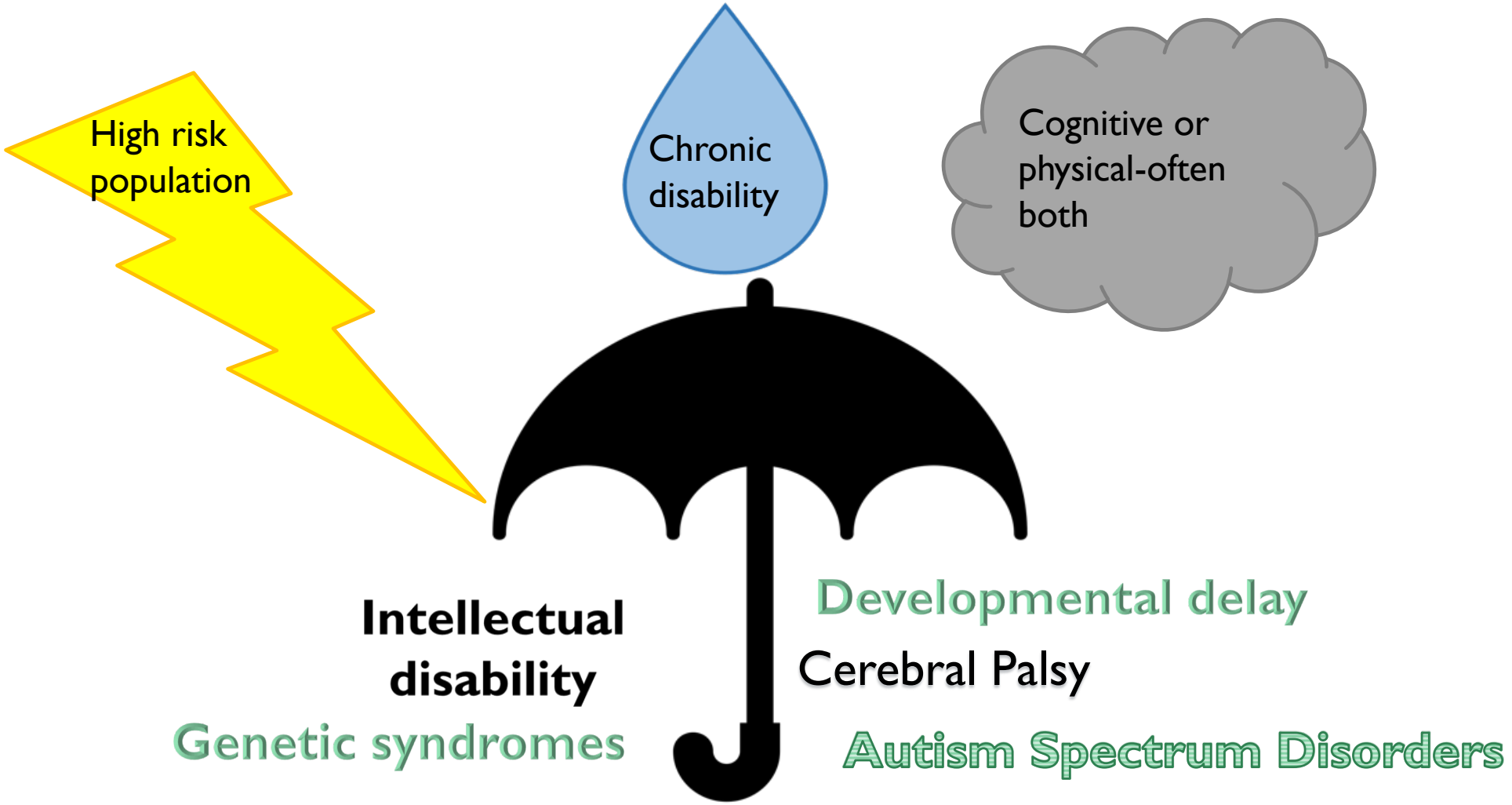
ASCEND DIAGNOSTIC & SUPPORT SERVICES

OUTLINE

- Overview of Autism and Developmental Disabilities
- Inequities and risk factors
- Role of community mental health providers
- How to provide care for this population

OVERVIEW OF INTELLECTUAL/ DEVELOPMENTAL DISABILITIES (IDDS)

WHAT ARE INTELLECTUAL/DEVELOPMENTAL DISABILITIES?



DEVELOPMENTAL DELAY

- A developmental delay is when a (young) child has significant delays in one or more of the following areas
  - Language
  - Motor skill
  - Cognitive skills
- A diagnosis of global developmental delay is given when a child has delays in multiple areas
- These diagnoses are often seen in young children
- Some children will "catch up" while others will go on to receive other diagnoses such as ID when they get older

INTELLECTUAL DISABILITY

- Three criteria must be met for a diagnosis of intellectual disability (ID)
  - Intellectual Disability
  - Significant limitation in intellectual functioning
    - Most often this is tested through an IQ test
  - Significant limitations in adaptive skills
    - Adaptive skills are skills of daily living
  - Disability must have originated before the age of 18
- Prevalence is about 1% of the population
- Presentation can range from mild to profound

AUTISM SPECTRUM DISORDER

- Autism Spectrum Disorder (ASD) is a diagnosis that has been receiving increased attention
- Current estimates are 1/54 children
  - Data & Statistics on Autism Spectrum Disorder
- The criteria for ASD
  - Persistent deficits in social communication and social interaction
  - Restricted, repetitive patterns of behavior, interests, or activities
  - Symptoms must cause impairment
- ASD can co-occur with many other symptoms and disabilities

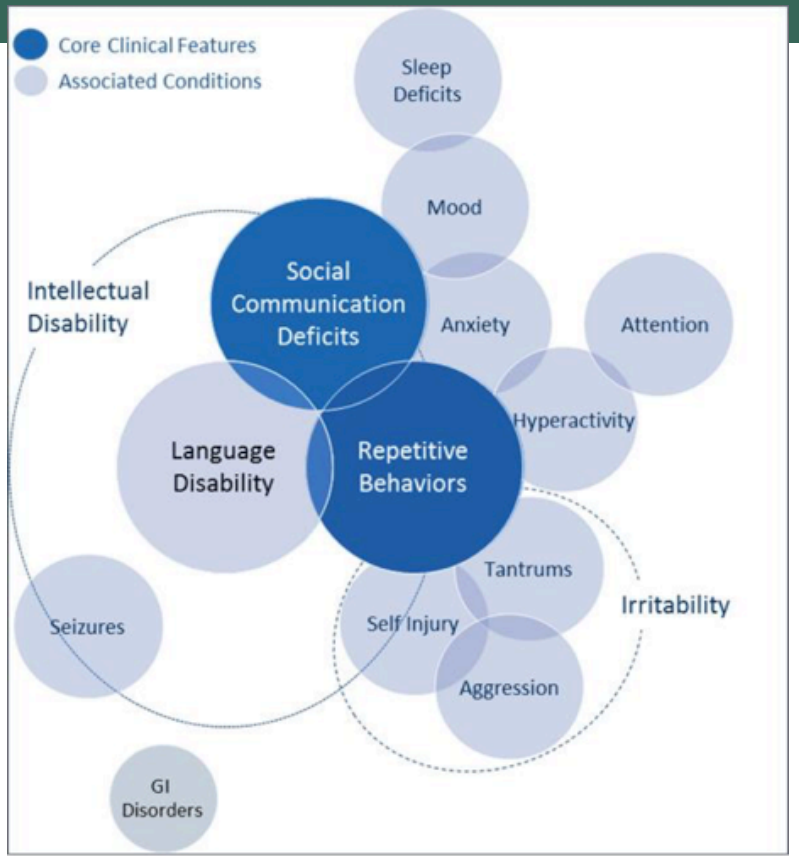


Image: Klinger, L., Dawson, G., Burner, K. &Crisler, M. Autism Spectrum Disorder. In E.J. Mash & R.A. Barkley (Eds.), (2014). *Child Psychopathology, 3rd* Guildford Press

GENETIC DISORDERS

- There are multiple disabilities caused by a mutation or change to genes or a chromosomal abnormality
- Some of these are inherited while others are random
  - Down syndrome
  - Fragile X syndrome
  - Prader-Willi syndrome
  - Angelman's syndrome
  - William's syndrome
- People with specific genetic disorders will often have facial features and other medical conditions associated with the disorder

CEREBRAL PALSY

- Cerebral palsy (CP) is disability that impacts a person's ability to move and maintain balance and posture.
- CP is caused by abnormal brain development or damage to the developing brain that affects a person's ability to control his or her muscles.
- People with CP have problems with movement and posture. Many also have related conditions such as ID, seizures, vision or hearing problems, speech delays and joint or spine problems.
- Prevalence is around .3% of children

WHAT CAUSES I/DDS?

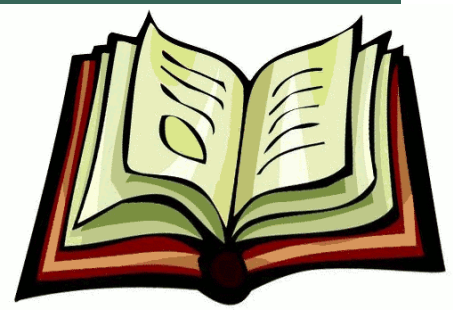
- Genetic causes
  - Inherited- Fragile X syndrome
  - Mutations/random- Down syndrome
- Problem during gestation, birth or early development
  - Drug or alcohol exposure in utero
  - Trauma during birth
  - Lead exposure
- Many cases of IDD are idiopathic
  - This means we don't know what caused them

MYTHS ABOUT PEOPLE WITH I/DD

- It will always be obvious when a person has a disability
- Knowing a person's disability can tell you a great deal about their behavior and abilities
- People with disabilities are unlikely to gain new skills or benefit from intervention
- People with disabilities can't have "normal" lives
- People with disabilities can't develop mental health problems or experience trauma
- If a person can't talk that means they don't understand what is being said around them

INEQUITIES AND RISK FACTORS

HISTORY: I/DD AND MENTAL HEALTH



- For many years it was believed that people with I/DD lacked the mental capacity necessary to develop psychiatric illness.
  - Freudian view of psychiatric disorders
  - People with I/DD were assumed to "not appreciate the factors (taboos, restrictions, training in habit and character formation) which in persons of higher intelligence cause mental conflicts"
  - As people with I/DD moved out of large institutionalized housing and into the community, their mental health care fell to community psychiatrists, most of whom were completely unequipped to work with people in this population
  - Psychotropic medication was heavily prescribed to this population, not to treat a diagnosed psychiatric disorder, but to control behavior

I/DD AND MENTAL HEALTH

- Growing recognition that people with I/DD experience mental health disorders
  - Prevalence of ICD-10 psychiatric disorders among children with I/DD was 39% as compared to 8.1% of typically developing children[1]
  - Relative risk of psychiatric disorder associated with intellectual disability ranged from 2.8 to 4.5[2]
- Research and public interest are (slowly) beginning to acknowledge how systemic treatment of people with I/DD may be a risk in and of itself
  - Societal stigma
  - Increased risk of living in poverty
  - Social isolation
  - Increased risk of experiencing trauma

I/DD AND TRAUMA

- People with I/DD are
  - **2x** as likely to experience emotional neglect, physical & sexual abuse
  - **3x** more likely to be in families with domestic violence
  - **4x** more likely to be victims of crime
  - **2x** more likely to be bullied
- Individuals with IDD are at increased risk for experiencing trauma
  - Experience high rates of out-of-home placements
  - Traumatic stress can lead to changes in learning, behavior & physiology—and may place children at risk for further trauma
    - Restraints, seclusion, ect.

I/DD AND TRAUMA

- People with I/DD are
  - Taught to obey authority
  - Often don't receive appropriate sex education
  - May struggle with communication or lack communication
- Individuals with I/DD and trauma are under-identified
  - Diagnostic overshadowing
  - Myths about disability – "He's fine."
  - Behavioral mind-set can miss signs of trauma
- Trauma impacts mental health, development, and behavior
  - Requires trauma-focused treatment

OUTCOMES FOR DUALLY DIAGNOSED YOUTH

- Youth with I/DD and mental health disorders have[3-5]
  - Longer and more frequent hospital admissions
  - Higher risk of out of home placements
  - Higher use of physical and chemical restraints (trauma)
  - High rates of polypharmacy
  - As they transition into adulthood they are less likely to be in competitive employment and engaged in their community

- Lack of longitudinal research on outcomes for dually diagnosed youth

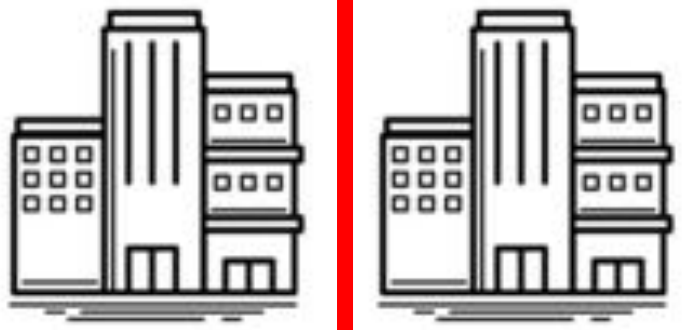
SYSTEMIC BARRIERS AND CHALLENGES TO DIAGNOSIS

- For people without disabilities, a mental health or trauma diagnosis generally follows a prescribed path.
  - The person or their parent refers to a medical professional
  - Interview for symptoms
  - Use of validated and reliable scales
- For people with I/DD
  - Dependent on others to refer
  - May be unable to participate in standard interview
  - Symptom presentation may be different- more behavioral
  - Few developed scales for this population
- Lack of mental health professional with competence in I/DD
    - Diagnostic overshadowing

SYSTEMIC BARRIERS AND CHALLENGES TO TREATMENT

- People with I/DD are generally connected to and receive services from the DD system
  - Often the mental health system will simply push anyone with I/DD back to the DD system regardless of the presenting problem
  - DD professionals are not trained to screen for or treat mental health/trauma
    - If trauma or mental health is the underlying problem, treatment from a strictly behavioral approach (how many DD professionals are trained) is unlikely to be effective and may exacerbate mental health and retrigger trauma
- The DD system is unprepared for mental health or trauma needs
  - Doesn't contract with mental health professionals
  - Doesn't consider trauma or mental health as needed services
  - No reimbursement for coordination between professionals

Siloed systems



ROLE OF COMMUNITY MENTAL HEALTH PROVIDERS

CASE EXAMPLE

- Katie*, 23 year old female
  - Diagnosed with ASD at 20 years old
  - Long history of depression
    - Suicide attempt after dx
    - Spent several weeks in inpatient
  - IQ around 80-not eligible for DD services
  - Part time job but needs a lot of support from Mother to make it to work, complete daily tasks
  - Very isolated, no hobbies, no friends
  - Anxiety surrounding
    - Menstruation
    - Wide range of social situations
    - Anxieties can lead to screaming, threats, property destruction in home

CASE EXAMPLE

- Thoughts?
- What symptoms are related to ASD versus mental health concerns?
  - How could you try to differentiate?
  - Does it matter? When would it matter?
- If I took away the fact that she has an ASD diagnosis do you think most clinicians would feel comfortable treating or diagnosing?
  - What about the ASD diagnosis changes things?

CONFIDENCE AND COMPETENCE

- Some psychologists, social workers and counselors are autism/disability experts and provide mental health care
  - Few and far between
  - Quickly become overwhelmed by requests
- Many mental health providers are concerned that they lack knowledge
  - Concern about practicing outside scope
- Many providers have the idea that the disability is ALWAYS the presenting concern or overshadows any other concern the individual is having
  - Lack confidence that they can help

MYTH BUSTING

- People with autism or developmental disabilities don't have mental health concerns or experience trauma
  - They sure do!
- It will always be obvious when a person has a disability
  - "Invisible" disabilitites
- "Regular" clinicians can't provide mental health care to people with disabilities
  - You know more than you think!
  - Willingness to learn and accommodate

MYTH BUSTING

- People with lower IQs won't benefit from mental health services
  - They sure can! (Sukhodolsky, Bloch, Panza & Reichow, 2013; Unwin, Tsimopoulou, Kroese & Azmi, 2016)
- If you don't know whether symptoms are mental health or disability related you can't provide treatment
  - Challenges are challenges
  - Many techniques overlap or require slight modifications

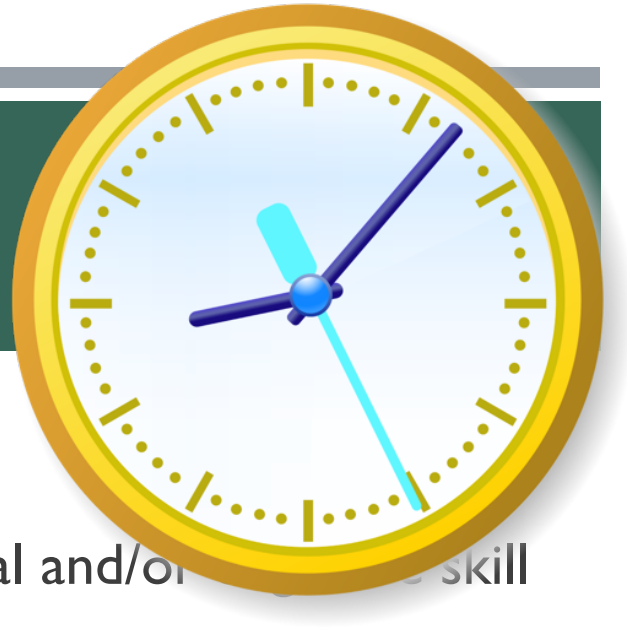
SMALL GROUP BREAKOUT DISCUSSION

- Do you currently see clients with autism or developmental disabilities in your practice?
  - If you do, how is it going?
  - If you do not, are you open to this? Why or why not?
- What are your main concerns around taking clients with autism or developmental disabilities?
- Have you encountered any of the myths that we discussed?
  - Why do you think myths like these persist?


BREAK
TIME!!!

PROVIDING CARE: PRACTICAL APPLICATION

GENERAL CONSIDERATIONS



- TIME!
  - By definition people with autism or other developmental have social and/or [illegible] skill deficits.
    - This is going to impact therapy!
    - Adjust your expectations
    - You should anticipate and plan for additional time and patience to be needed
      - Manualized treatments are going to take longer
      - May need longer sessions (document this need and the reason behind it)

GENERAL CONSIDERATIONS

- Gather information in advance but don't make assumptions
  - It may be helpful to ask people who know the individual how they best communicate/what they need to be successful
    - Some people may use a communication device
  - Review psychological reports/IEP to understand their disability and make a plan
  - Be ready and willing to "go with the flow" and adapt to the individual
    - Some people will have much more ability to communicate than people around them give them credit for
      - Be patient and help people communicate to the best of their ability

GENERAL TECHNIQUES

- Slow down
- Use simple, concrete language
- Break big or open ended questions into smaller questions
  - Do you like you new house or your old house better?
    - Do you like your new house? Did you like your old house?

GENERAL TECHNIQUES

- Visuals
  - Have some ready or pull out your phone and use google images
- Schedules
  - Use your phone as a timer
- Breaks
  - Airplane example
- Check for comprehension
  - Especially important around consent forms

STANDARDIZED TOOLS

- Often scales or standardized questions are used to gather information
- These are generally created and/or normed with typically developing people in mind.
  - Very few scales have been developed/normed for people with developmental disabilitites
  - Adaptations often need to be made for people with developmental disabilities to access

UCLA PTSD Reaction Index for Children/Adolescents DSM-5 ©

HOW MUCH OF THE TIME DURING THE PAST MONTH…		None	Little	Some	Much	Most
$1_{(1)}$	I am on the lookout for danger or things that I am afraid of (like looking over my shoulder even when nothing is there).	0	1	2	3	4
$2_{(2)}$	I have thoughts like "I am bad."	0	1	2	3	4
$3_{(3)}$	I try to stay away from people, places, or things that remind me about what happened.	0	1	2	3	4
$4_{(4)}$	I get upset easily or get into arguments or physical fights.	0	1	2	3	4
$5_{(5)}$	I feel like I am back at the time when the bad thing happened, like it's happening all over again.	0	1	2	3	4
$6_{(6)}$	I feel like what happened was sickening or gross.	0	1	2	3	4
$7_{(7)}$	I don't feel like doing things with my family or friends or other things that I liked to do.	0	1	2	3	4
$8_{(8)}$	I have trouble concentrating or paying attention.	0	1	2	3	4
$9_{(9)}$	I have thoughts like, "The world is really dangerous."	0	1	2	3	4
$10_{(10)}$	I have bad dreams about what happened, or other bad dreams.	0	1	2	3	4
$11_{(11)}$	When something reminds me of what happened I get very upset, afraid, or sad.	0	1	2	3	4
$12_{(12)}$	I have trouble feeling happiness or love.	0	1	2	3	4
$13_{(13)}$	I try not to think about or have feelings about what happened.	0	1	2	3	4
$14_{(14)}$	When something reminds me of what happened, I have strong feelings in my body (like my heart beats fast, my head aches or my stomach aches.	0	1	2	3	4
$15_{(15)}$	I am mad with someone for making the bad thing happen, not doing more to stop it, or to help after.	0	1	2	3	4
$16_{(16)}$	I have thoughts like "I will never be able to trust other people."	0	1	2	3	4
$17_{(17)}$	I feel alone even when I am around other people.	0	1	2	3	4
$18_{(18)}$	I have upsetting thoughts, pictures or sounds of what happened come into my mind when I don't want them to.	0	1	2	3	4
$19_{(19)}$	I feel that part of what happened was my fault.	0	1	2	3	4
$20_{(20)}$	I hurt myself on purpose.	0	1	2	3	4
$21_{(21)}$	I have trouble going to sleep, wake up often, or have trouble getting back to sleep.	0	1	2	3	4
$22_{(22)}$	I feel ashamed or embarrassed over what happened.	0	1	2	3	4

TECHNIQUES FOR LIKERT TYPE QUESTIONS

- Use visuals to help

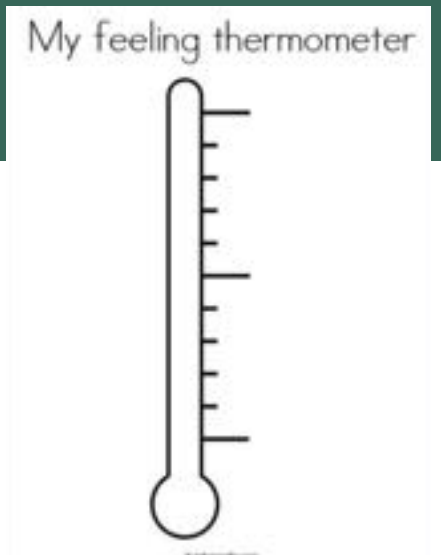
RED FLAGS/ THINGS TO WATCH OUT FOR

- Acquiescence
- Scripting
  - In context versus out
- Alternating responses
- Responding without understanding
- Temporal anchoring issues

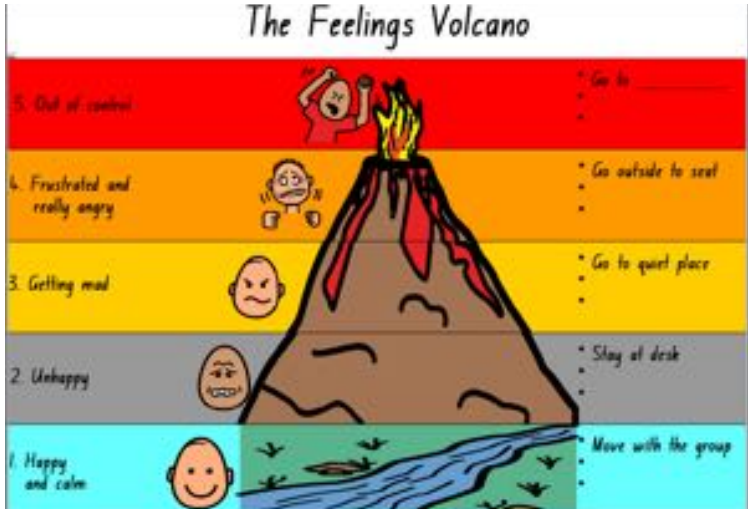
ACCOMMODATIONS

- Don’t make assumptions about what the most pressing concern is
  - Ask, talk to the client about what they want/need
  - Eg. Friendships
- Cognitive and language differences
  - For clients with lower cognitive/verbal abilities
  - Focus on the B in CBT
  - Work on teaching skills versus insight based therapy

ACCOMMODATIONS



- Social communications differences
  - Often very concrete
    - Be clear, direct, no euphemisms or abstract terms
  - Visual information can be helpful to explain abstract concepts
    - Hands on activities and PRACTICE
  - May need "background information"
    - Don't make assumptions about what they know



ACCOMMODATIONS

- Environmental
  - Help meet sensory needs/sensitivities
    - Quiet room, lower the lights, sit side by side ect
    - Engage with an activity versus sit and talk
  - Various formats
    - Visual information can be extremely helpful
    - Technology and apps

ACCOMMODATIONS

- Family/Caregiver involvement
  - Parents or caregivers often more involved than would be expected for same aged peers
  - Clear conversations
  - Lean on families to build on and support new skills

CURRENT CASE EXAMPLE 1

- 21 year old with ASD and ID
  - Mood SX and aggressive behavior
  - Began after a family vacation that went poorly, very difficult on client and family
  - 60 minute sessions on Telehealth 1x per week
  - 30 minutes with client alone
    - Schedule
    - Tasks
  - 30 minutes to debrief session with parents and provide parent training on handling aggression in the home

CURRENT CASE EXAMPLE 11

- 10 year old with ASD, no cognitive disability
  - Very rigid and intense specific interests in specific cartoon characters
- Extreme anxiety, avoidant behavior, self-injury
  - SX have increase significantly during pandemic, made worse by dad's mental health
- 60 minute session on telehealth
- Using a manualized treatment for anxiety: Coping Cat
  - Moving slowly each- 2/3 sessions for each module
    - Bringing in his interests
    - Leaving time for each session for "what you want to talk about"
  - Coordinating with Mom so she can support and also to provide her with suggestions around avoidant and self-injury

SMALL GROUP CASE EXAMPLES

- Read your case with your small group
- What are your initial thoughts and impressions?
  - Can you take this client?
  - What are your concerns?
- What accommodations might this client need?
  - Are there scales that you might want to use? Will they need to be modified?
- How might you use your existing skills effectively for this client?

WRAP-UP & RESOURCES

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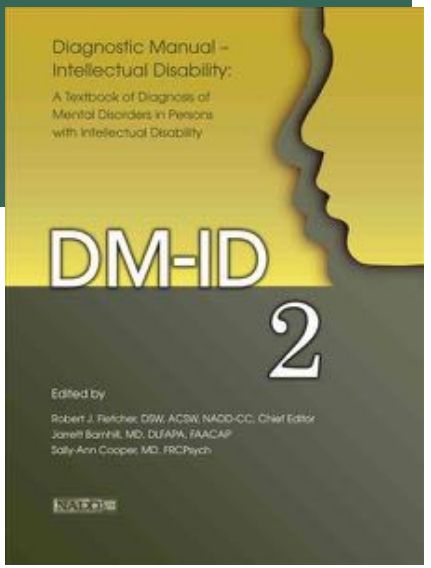

- http://thenadd.org/
  - The NADD is an organization for people with I/DD and mental health care needs
  - Trainings, resources, annual conference
- https://www.nctsn.org/
  - The National Child Traumatic Stress Network provides trainings, resources, and tool review for childhood trauma.
  - They have a training specific to I/DD and trauma
- The DM-ID 2 is a companion book to the DSM-5 to aid in diagnosis of mental health disorders in people with I/DD

WRAP-UP & RESOURCES

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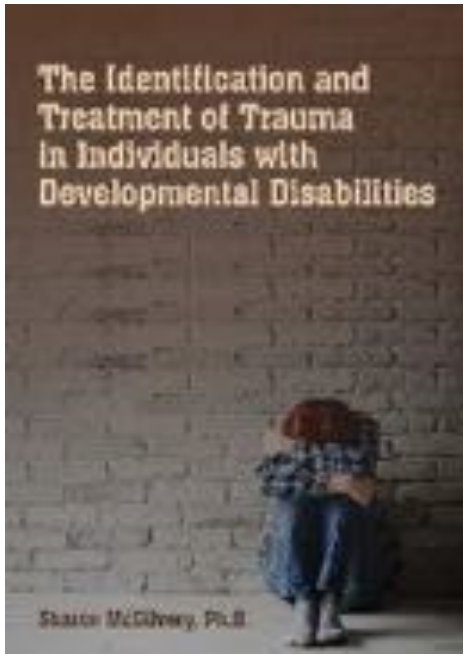

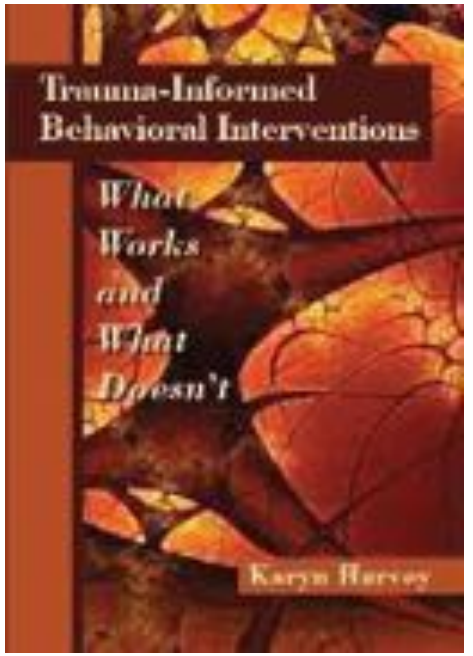


THANK
YOU!