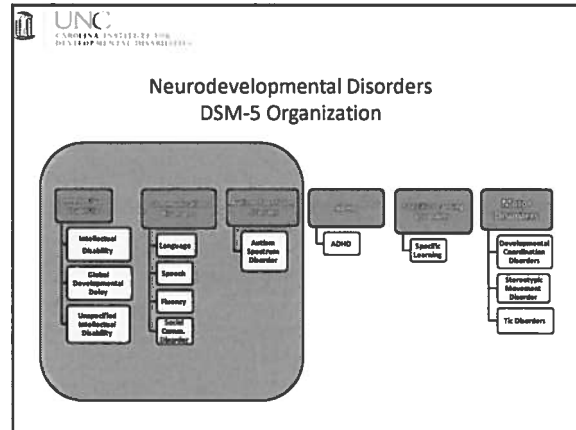


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## Co-occurring Mental Health and Behavioral Disorders in Children and Adolescents with Intellectual and/or Developmental Disabilities

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### Challenges in MH/IDD

- Psychiatric or mental health disorders are estimated as 2 to 4 times more likely in individuals with intellectual and developmental disabilities.
- Determining an accurate psychiatric diagnosis is difficult especially as the level of functioning or intellect declines.
- Researchers have found as many as 1/3 of individuals with ID have significant behavioral, mental, or personality disorders requiring MH services.

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### What makes individuals with I/DD vulnerable to mental health problems?

<b>Biological</b>	<ul style="list-style-type: none"> <li>• Brain damage/epilepsy (high rate of CNS impairment)</li> <li>• Genetic conditions or vulnerabilities (behavioral phenotypes)</li> <li>• Physical illness</li> <li>• Sensitivity to medication side effects</li> <li>• Vision/hearing impairments</li> </ul>
<b>Psychological</b>	<ul style="list-style-type: none"> <li>• Trauma including physical and sexual abuse</li> <li>• Delayed development of coping/problem solving skills (skills taught through language)</li> <li>• Internalization of degrading messages</li> <li>• Delayed development of affect/emotional regulation</li> <li>• Delayed development of communication ability</li> </ul>
<b>Social</b>	<ul style="list-style-type: none"> <li>• Social exclusion/bullying/rejection</li> <li>• Limited social supports</li> <li>• Negative expectations</li> <li>• Poor access to quality services</li> <li>• Financial challenges</li> </ul>

Fletcher, Baker, St. Croix, & Chepkic, 2015

### Having co-occurring I/DD and a psychiatric disorder can have serious effects on the person's daily functioning.

- Hinder educational progress
- Interfere or inhibit vocational activities
- Jeopardize residential placements
- Disrupt family and peer relationships
- Reduce quality of life
- Exacerbate behavioral upset

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### Individuals with Co-Occurring MH and I/DD are at Increased Risk for

- communication impairments
- behavior challenges
- self-injury (head banging, skin picking)
- repetitive behavior patterns
- repetitive speech patterns
- noncompliance
- aggression
- complex sensory needs
- emotional dysregulation
- confusion

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## Prevalence

1.6% of the general population is estimated to have an intellectual disability  
 (5 million people in the US)

1/3 of people with an intellectual disability may have a diagnosable psychiatric disorder  
 (approximately 1.6 million in the US)

Children with I/DD are often at significantly greater risk of exposure to forms of social disadvantage. In studies when social disadvantage is controlled for, there is reduced risk of psychiatric disorders among children with I/DD.

Fletcher, Baker, St. Croix, & Cheplic, 2015  
 Emerson & Hatton, 2007

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## Co-morbidity of ASD and Co-Occurring Disorders

A Venn diagram with five overlapping circles. The central circle is labeled 'ASD'. It overlaps with 'Tic' (top-left), 'Anxiety' (left), 'ADHD' (bottom), and 'OCD' (right). The intersections between these circles represent co-occurring conditions.

## Barriers to Diagnosis and Treatment

- Training for professionals and services are siloed
- Diagnostic overshadowing
- Unusual presentations of MH health disorders in those with I/DD
- Polypharmacy
- Communication deficits
- Unrecognized or untreated medical conditions
- Learned behavior
- Sensory impairments

## Diagnostic Manual for Intellectual Disabilities (DM-ID)

- The *DM-ID* was developed as a companion guide to the *DSM-IV-TR* in 2007
  - was the product of a collaborative effort involving the APA and the NADD
- Provides a more systematic way to diagnose psychiatric disorders in persons with I/DD with more accuracy

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## Bio-psychosocial Approach

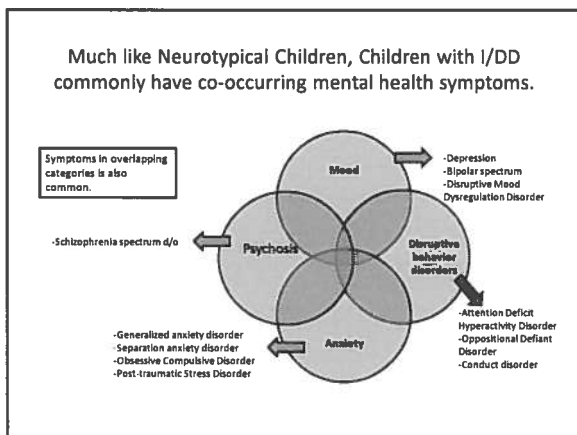
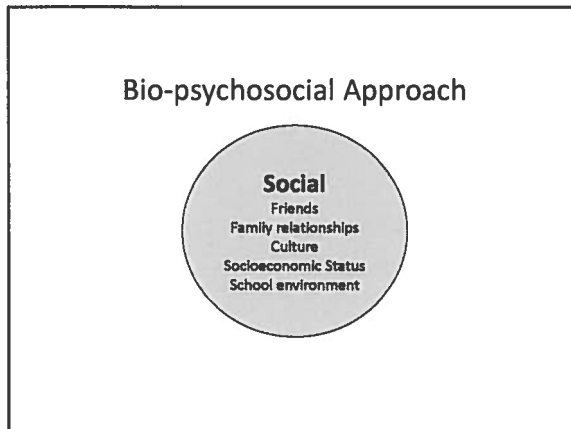
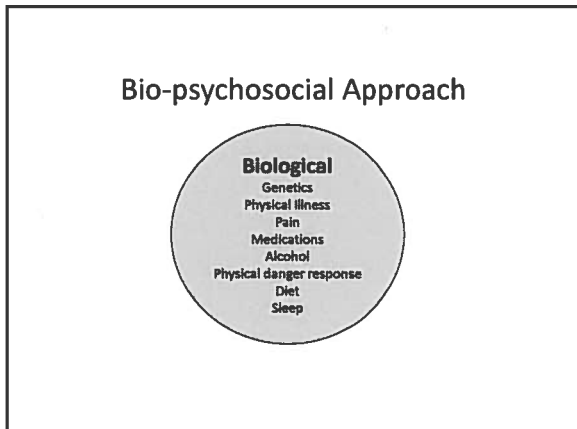
A Venn diagram with three overlapping circles labeled 'Psychological', 'Biological', and 'Social'. The intersections represent the integrated nature of these domains in a bio-psychosocial approach.

Fletcher, Baker, St. Croix, & Cheplic, 2015

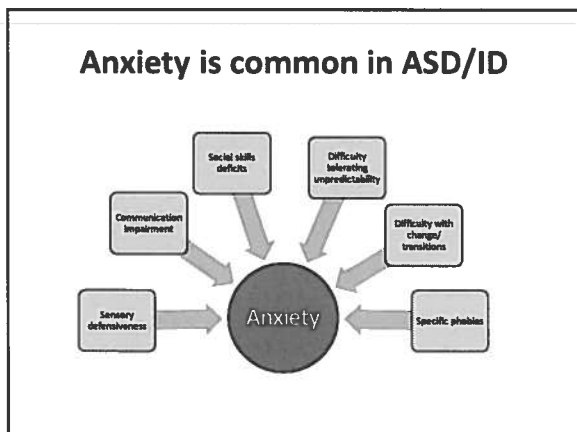
## Bio-psychosocial Approach

A large circle containing the following list of psychological factors:

- Psychological
  - Learning
  - Emotions
  - Cognition
  - Memory
  - Coping skills
  - Beliefs
  - Stress Management
  - Behavioral Strategies



## Anxiety



- ### Unique Anxiety Symptoms in I/DD
- Fear of unexpected noises
  - Upset by change and transition
  - Difficulty with novel experiences/people
  - Routine-Bound
  - Requiring frequent reassurance (repetitive questioning)

### Treating Anxiety in I/DD

- Address specific sources of anxiety with behavioral interventions first:
  - **Sensory defensiveness:** Occupational therapy, noise-cancelling headphones, avoidance of overstimulating situations, self-soothing strategies
  - **Difficulty tolerating unpredictability / change:** Use social stories, previewing new situations, written/ picture schedules, transitional objects, visual timers, graded exposure, rewarding effort
  - **Social anxiety:** Social skills instruction, modified CBT
  - **Fears/ phobias/ compulsions:** modified CBT (graded exposure)

### Treatment for anxiety may require adaptation in ID/D.


For higher-functioning individuals and those with good language, cognitive behavioral therapy (CBT) is evidence based

- May need to simplify language and concepts, depending on cognitive ability
- Greater emphasis on behavioral interventions, including stress management techniques (rather than cognitive restructuring)
- Increased parent/caregiver involvement
- May need to include social skills instruction
- Consider personalizing treatment to child's special interests

For lower functioning and preverbal children/adolescents, interventions will target modifying the environment instead.

- Examples: noise cancelling headphones, visual schedules, avoidance of overstimulating environments, structured environments, sensory diet

For severe anxiety, medications include SSRIs and buspirone, though often not tolerated as well in children as in adults.





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## Irritability

(Symptom not Disorder)


### Irritability is common to a number of disorders.

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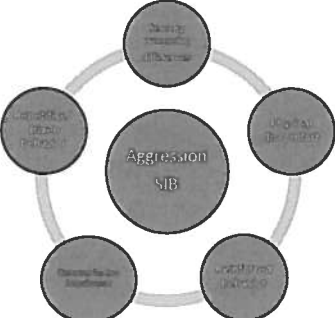
### Irritability: Common Behavioral "Functions"

- Escape/ Avoidance
- Want access to desired activities or objects
- Difficulty communicating wants/needs
- Communication of discomfort
- Communication of frustration
- Seeks attention from others
- Internally driven
  - Compulsive/repetitive behavior
  - Need for sensory input




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### Irritability and Aggression: Contributing Influences



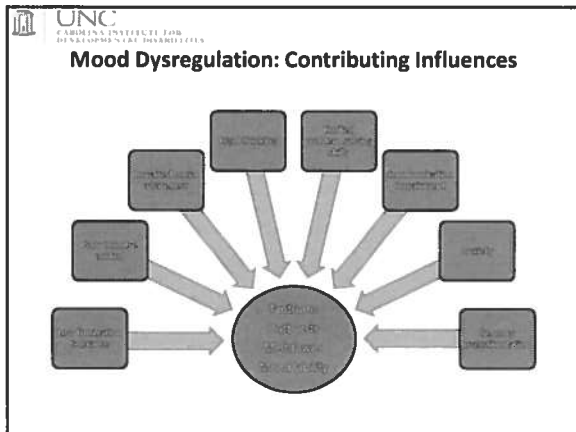
### Irritability leading to Aggression Considerations for Treatment

- Consider behavioral therapy as first-line for mild to moderate irritability
  - ABA is gold standard
- Treat medical and recognizable psychiatric conditions first
  - Is this a medication side effect?
  - Is this a symptom of another disorder?
- Optimize communication supports
  - PECs cards, written schedules, AAC program
- Use severity of behaviors to guide risk/ benefit of medication



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## Mood Disorders



### Risk Factors for Depression

Biological	<ul style="list-style-type: none"> <li>• Low birth weight</li> <li>• Family history of depression and anxiety</li> <li>• Traumatic brain injury</li> <li>• Chronic illness</li> </ul>
Psychological	<ul style="list-style-type: none"> <li>• Gender dysphoria</li> <li>• Negative coping style</li> <li>• Other MH diagnoses: anxiety, SA, LD, ADHD, ODD</li> </ul>
Social	<ul style="list-style-type: none"> <li>• Family dysfunction or conflict</li> <li>• Poor child-parent personality fit</li> <li>• Bullying/peer problems</li> <li>• Poor social support</li> <li>• Poverty</li> <li>• Early exposure to abuse and neglect</li> <li>• Academic problems</li> </ul>

### Features of Depression in I/DD

Must express either:

- (1) Depressed or irritable mood**
  - Children and those with cognitive disability are less able to identify and express emotions, and may manifest irritability rather than sadness
  - everything is “unfair,” others are mean or uncaring, brooding, often annoyed or grouchy.
- (2) Decreased interest or pleasure (anhedonia)**
  - Labels experiences as “boring” or “stupid”
  - Loses interest in friendships, playing, extracurricular activities
  - Anticipates events but feels disappointed when they arrive

### When Considering Depression in I/DD

**Consider medical explanations first**

- Seizures, dental pain, constipation, reflux, ear infection, etc.
- New medications (especially psychotropics, seizure medications)
- High suspicion of medical if non-verbal with sudden onset behavior change

**Assess for environmental contributors**

- Changes to normal routine, change in caregivers, major life transition, trauma

**Assess for psychiatric comorbidity**

- Mood disorder, anxiety, psychosis

**Inventory of antecedents and consequences**

- What function does the behavior serve?

**Safety assessment**

- Serious risk of injury to self or others

### Features of Depression: Manifestation in I/DD

Feature	Typical Manifestation in Individuals with I/DD
Sleep disturbance	<ul style="list-style-type: none"> <li>Sleeping more than 12 hours per day</li> <li>Frequent naps</li> </ul>
Loss of Interest	<ul style="list-style-type: none"> <li>Refusal to participate in usual activities including school and fun</li> <li>Spending more time alone</li> <li>Loss of interest in reinforcers that worked</li> </ul>
Guilt	<ul style="list-style-type: none"> <li>"I'm dumb," "I'm stupid"</li> <li>Social isolation</li> <li>Seems to seek punishment</li> </ul>
Loss of Energy	<ul style="list-style-type: none"> <li>More frequent breaks for even simple tasks</li> <li>Inability to complete tasks</li> <li>Slumping or looking tired</li> </ul>
Difficulty Concentrating	<ul style="list-style-type: none"> <li>Reduction in usual academic/work output work</li> <li>Inability to stay with tasks that could previously</li> <li>Decrease in IQ scores if tested</li> </ul>
Change in Appetite	<ul style="list-style-type: none"> <li>Disruptions at meals or refusal to come to meals</li> <li>Constantly seeking food</li> </ul>
Psychomotor agitation or slowing	<ul style="list-style-type: none"> <li>Restlessness, fidgeting, pacing</li> <li>Increased disruptive behavior</li> </ul>
Suicidality—thoughts or plans	<ul style="list-style-type: none"> <li>Preoccupation with a loved one's death</li> <li>Talking about suicide</li> <li>Fascination with violent movies</li> <li>Unconventional suicide attempts (running in front of traffic)</li> </ul>

Fletcher, Baker, St. Croix, Chepic 2015

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### Depression can lead to functional impairment in multiple areas

- Academic decline
- Social withdrawal
- Interpersonal difficulty with family and friends

**Potential Secondary Problems**

- School absence or refusal
- Sexual acting out
- Excessive risk-taking
- Substance misuse

### Potential Treatment Interventions for Depression

- Therapy—individual or group
- Regular exercise
- Regular scheduling of pleasurable activities
- Learning stress management
- PMR, deep breathing, mindfulness
- Social skills training
- Positive environment and support strategies
- Antidepressant medication (last resort)

Fletcher, Baker, St. Croix, Chepic (2015)

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### Depression in ASD

- Prevalence of depression in ASD is high
- Likely more common with higher-functioning ASD, greater social awareness
- Contributing factors:
  - Social isolation
  - Bullying
  - Impaired adaptive functioning, difficulty attaining independence
- Challenges in identifying depression in ASD:
  - Overlap with core ASD symptoms (impaired emotion regulation, irritability, reduced affect, social withdrawal, limited interests, sleep disturbance)
  - Difficulty recognizing and describing emotions
  - Language impairment
  - No ASD-specific rating scales for mood

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### Depression in ASD

- Is this depression?
  - Verbal screen for depression in patients capable of self-report
  - Consider depression in lower-functioning patients with decline from baseline functioning
  - Use family history to help evaluate risk
- CBT, social skills are first-line interventions for mild to moderate depression
  - CBT may need to be modified

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### Bipolar Disorder

- Diagnosis in children has been controversial
- Strictly defined, bipolar disorder is characterized by episodes of **mania, hypomania, and major depression.**
- Is **not** defined solely by irritable mood, which is a symptom of many mental health and developmental disorders.
- Strong genetic risk
  - Family history helps predict risk (relatives w/ psychosis or mania, suicides, substance abuse, hospitalizations)
- Broad differences in prevalence by country

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### Bipolar disorder

- Estimated lifetime prevalence 1-2%
  - Occurrence in children is less clear, and prevalence reports vary by referral source
- About 80% of risk due to genetic factors
- Children of adults with bipolar disorder have about 25-fold increased risk of developing bipolar disorder (compared to children of adults without bipolar disorder)
- High co-occurrence with ADHD, ODD, and CD
- It is challenging to diagnose bipolar in children with I/DD due to increased cognitive and social communication impairments, impulsivity, and difficulty regulating mood

### Symptoms of mania: Elevated or irritable mood with increased energy

- Distractibility
- Increased movement and restlessness (psychomotor agitation)
- Grandiosity (belief in special status, power, or abilities)
- Flight of ideas (racing thoughts)
- Increase in goal-directed Activities (e.g., taking on big projects but failing to finish them; risk-taking behaviors)
- Decreased need for Sleep
- Excessive Talking/ pressured speech

### Affective Disorders: Bipolar Disorder in ASD

- Prevalence of BPAD in ASD cohorts~ 5-7% Low concordance between community diagnoses and structured interviews
- Mood lability, irritability in ASD may be misdiagnosed as BPAD
- Most BPAD cohorts, clinical trials exclude ASD
- Standard BPAD diagnostic criteria should be applied


(Skokausas 2015)

### Disruptive Mood Dysregulation Disorder (DMDD)

- New in DSM-5
- Intended to distinguish chronic irritable mood from bipolar disorder
- NOT attributed to other developmental disorder
- Trajectory still uncertain, but may predict later depression and anxiety disorders.
- Best practice treatment options unclear. Treat co-occurring disorders, such as ADHD and anxiety.

### DMDD: Diagnostic Criteria

- Hallmark is **severe, recurrent temper outbursts** (verbal or physical)
- Outbursts are clearly out of proportion to the situation and *inconsistent with developmental level*
- Outbursts occur  $\geq 3$  times per week
- **Mood between outbursts is irritable or angry almost all of the time**
- Symptoms present for at least 12 months, in at least 2 settings (e.g., home and school)
- Diagnosed *after* age 6 but *before* age 18, with onset by age 10
- Symptoms not better accounted for by another primary diagnosis (e.g., autism spectrum disorder, PTSD, MDD)
- \*Cannot be diagnosed together with ODD or bipolar disorder

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## Psychosis & Schizophrenia

### Psychosis

- Both are neurodevelopmental disorders and may share underlying genetic and environmental risk factors.
- Consistent demonstration of elevated rates of ASD and schizophrenia spectrum disorders (SSD) co-occurrence
  - Mean incidence of **12.8%** of SSD in ASD in 14 studies (Chisolm et. al., 2015)
- Individuals diagnosed with schizophrenia in adulthood were frequently diagnosed with ASD in childhood.
  - Shared early cognitive and social deficits
- Some genetic disorders are associated with both schizophrenia and ASD (e.g., 22q11 deletion (DiGeorge) syndrome)

### Diagnostic Challenges ASD Trait Overlap

#### Positive Symptom Overlap

- Difficulty distinguishing reality from fantasy
- Unusual, strongly held beliefs
- Abnormal speech (perseveration, self-talk, odd tone)
- Abnormal thought processes (incoherence, paranoid/referential thinking)

#### Negative Symptom Overlap

- Blunted affect
- Amotivation/ avolition
- Poverty of speech
- Social withdrawal
- Impaired adaptive functioning

Impaired self-report  
Shared features of social and communication deficits



### Psychosis in ASD: Clinical Features

- Decline from baseline functioning
- Presence of new onset delusions or hallucinations
- Change in intensity of magical thinking, blurring of reality/fantasy
- Co-occurring change in mood
- \*Change from usual functioning is key

### Psychosis in ASD: Treatment

- No controlled trials for ASD + psychosis
- Follow recommended treatment guidelines for psychosis in children without ASD
- Behavior-based therapy can also help
  - ABA for lower functioning/ less verbal
  - Modified CBT for higher-functioning



### Trauma in IDD

### What is Traumatic Stress?

- An individual experiences or witnesses a real or perceived threat to their emotional and/or physical well-being
- The intensity of the experience affects the individual
- The individual's reactions persist and interfere with aspects of their functioning even after the traumatic events have ended

Of note:

Not all people who experience a traumatic event or stress will go on to develop symptoms

Road to Recovery, 2015

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## Prevalence Rates in IDD

Trauma is higher in children with intellectual/developmental disabilities compared to children without disabilities:

- 2 x more likely to experience physical and sexual abuse
- 4 x more likely to be victim of a crime
- 2 x more likely to experience emotional neglect
- 3 x more likely to be exposed to domestic violence
- 1.5-2 x more likely to be bullied
- Increased exposure to physical restraint/seclusion and intrusive medical procedures

The Road to Recovery, 2015

## Correlations with Prevalence Rates

- Externalizing behavior (which is increased in IDD) is related to an increased risk of *physical abuse*
- Increased vulnerability to sexual abuse is correlated with:
  - higher incidence of early puberty
  - multiple caregivers providing intimate care
  - communication barriers
  - learning problems
  - residential care

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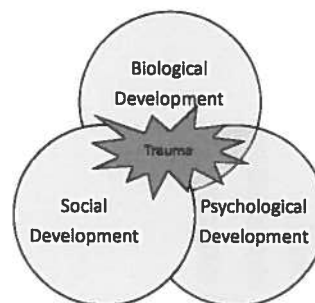
## Increased Risk for Maltreatment

Individuals with IDD are at increased risk for maltreatment due to:

- significant care requirements
- challenging behaviors
- difficulty with self-report
- increased mental health and developmental problems in parents
- increased bullying and targeting from peers
- vulnerability to exploitation and manipulation

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## Trauma impacts all areas of development



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## Widespread effects of childhood trauma

- **Emotional:** Significant increase in risk for mood and anxiety disorders, disruptive behavior disorders, attachment disorders, and substance abuse.
- **Cognitive:** Severe neglect and abuse in childhood is associated with lower IQ
- **Behavioral:** Increased rates of aggression, motor stereotypy, poor academic performance.
- **Physical:** Severe abuse and neglect associated with poor growth
- **Social:** May appear withdrawn and detached or indiscriminantly social

Recovery is possible with treatment and consistent, stable, safe environment

## Why is Assessment of Trauma Tricky in IDD?

- Difficulty determining if behavior is related to trauma/stress or known developmental challenges
- Behavioral phenotypes within genetic conditions
- Co-occurring medical problems
- Co-occurring mental health conditions
- Communication challenges
- Challenges finding dually trained professionals
- Diagnostic overshadowing

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## Why is Assessment of Trauma Tricky in IDD?

- Individuals with IDD often have fewer protective factors to reduce the impact of adverse effects
  - Less social support
  - Social rejection/stigmatization
  - High rate of central nervous system impairment
- Individuals with IDD may have fewer sources of relief than others
  - Limited communication may:
    - reduce their ability to report harm
    - limit the relief from expression of feelings
    - limit ability to seek relief and/or describe their needs
    - limit effective verbal based coping mechanisms

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## Overshadowing

When an individual's disability or disabilities prevents professionals and/or caregivers from looking beyond the disability for the root of a symptom/behavior. In attributing challenging behaviors solely to the disability, they fail to assess for possible mental or physical illness, or trauma.

Overshadowing reduces the likelihood of identifying individuals who have experienced trauma and achieving appropriate treatment protocols.

Those with IDD are therefore offered services related solely to their developmental disabilities.

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## Adapting a Trauma Screen for Individuals with IDD

- May need information from multiple caregivers
- Caregivers may need psychoeducation on common responses to trauma
- When questioning individuals with IDD, adaptations may be needed, such as:
  - Slowed pace of speech and questioning
  - Simplification of language
  - Presentation of concepts one at a time
  - Concrete examples (e.g., draw bodies, use dolls, etc.)
  - Use of questions that build on individual's strengths
  - Utilization of an interpreter, person more aware of communication style, or someone with knowledge of assistive devices

Road to Recovery, 2015

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## Possible trauma-related symptoms in IDD

- Deterioration in mood
- Anxiety/ PTSD symptoms
- Developmental regression (e.g., bedwetting, thumb sucking, baby talk, decreased ADLs)
- Reduced use of language or other forms of communication
- Heightened repetitive behaviors (e.g., body rocking, pacing)
- Increased social withdrawal
- Agitation, physical aggression, or self-injury
- Sexualized behaviors (e.g., frequent masturbation, attempts to inappropriately touch others)
- Intense and specific new fears linking to the original danger
- Unexplained weight loss or weight gain

## Possible trauma-related symptoms in IDD

- Changes in eating and sleeping (nightmares)
- Heightened startle response
- Confusion about what is dangerous
- Fear of being separated from familiar people/places
- Unwanted and intrusive thoughts/images
- Preoccupation with moments from the traumatic experience
- Behavior may fluctuate between being avoidant and recklessness
- Concentration challenges
- Somatization


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## Treatment for Trauma in IDD

Treatment of trauma-related symptoms for individuals with IDD is similar to those used for typically developing individuals, but requires some modifications for IDD

Adapted trauma informed interventions:

- Trauma-focused CBT (TF-CBT) is treatment of choice, if cognitively able
- Dialectical Behavior Therapy (DBT)
- Parent-Child Interaction Therapy (PCIT)
- Child-Parent Psychotherapy (CPP)
  - (e.g., "Triple P" Program)
- Positive Identity Development


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## Restricted and Repetitive Behaviors


### Restricted and repetitive behaviors (RRB)

**DSM-5 Category B criteria (must have  $\geq 2$ ):**

- Stereotyped or repetitive motor movements, use of objects, or speech
- Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal and nonverbal behavior
- Highly restricted, fixated interests that are abnormal in intensity or focus
- Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment

### Restricted and repetitive behaviors (RRB)

Repetitive behaviors exist on a continuum:




<p><b>"Lower Order"</b></p> <ul style="list-style-type: none"> <li>– Simple motor stereotypy</li> <li>– "Stimming"</li> <li>– Motor and vocal tics</li> </ul>	<p>– Complex but purposeless movements</p>	<p><b>"Higher Order"</b></p> <ul style="list-style-type: none"> <li>– Complex rituals and routines</li> <li>– OCD-like compulsions</li> </ul>
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### RRB: When is it a problem?

- **Not all repetitive behavior warrants intervention**
  - Is it causing the child distress?
  - Is it otherwise interfering with expected functioning?
  - Is it disruptive to sleep or causing health problems?
  - Is it severely disruptive to family life?
- **Restricted interests can be useful**
  - Use of a preferred activity or object as a reward
  - Shared interest leading to friendships (e.g., Legos, Minecraft, history)
  - Basis for a career path

### RRB: Recommended Behavioral Strategies (Level 0)

- Best accomplished via a comprehensive behavioral therapy program
- Provide a high level of structured activity
- Distract and redirect when possible
- Use special interests as a reward for expected behavior
- Allow downtime for "stimming," frequent movement breaks
- Provide clear rules for conversations about interests
  - e.g., Limit talk about favorite topic to 5 min, 3 times per day.
- Provide sensory outlets (e.g., use of fidget toys, massage, "heavy work", trampolines, swings)


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## Self-Injurious Behavior in IDD

### Overview of Self-Injurious Behavior (SIB)

Self-injury in I/DD may take several forms:

- Head banging (with hand or against surfaces)
- Biting (often on the hand, wrist or arm)
- Slapping
- Scratching
- Self-mutilation (e.g., poking at self with sharp objects, tearing at fingernails, pulling out hair, cutting self)

\*Caregivers should take a careful inventory of a child's self-harm behaviors, including the frequency, severity, and proposed function of each to guide intervention.

### Careful analysis often reveals a predictable function(s) for SIB.

A Functional Behavioral Analysis (FBA) can help determine the functions of SIB through close observation and data collection.

### Treatment of SIB depends upon the function of the behavior.

<b>Automatic reinforcement</b>	<ul style="list-style-type: none"> <li>• Provide "sensory diet" to meet sensory input needs</li> <li>• Frequent breaks for physical activity</li> </ul>
<b>Escape or avoidance</b>	<ul style="list-style-type: none"> <li>• Ignore low-level SIB</li> <li>• Provide frequent breaks, choices between activities, and incentives for cooperation</li> </ul>
<b>Access to desired objects</b>	<ul style="list-style-type: none"> <li>• Set attainable goals that allow the child to work towards desired objects and activities</li> </ul>
<b>Attention</b>	<ul style="list-style-type: none"> <li>• Ignore low-level SIB</li> <li>• Provide praise and positive reinforcement for desired behaviors</li> </ul>
<b>Pain or discomfort</b>	<ul style="list-style-type: none"> <li>• Recognize and treat the source of physical discomfort</li> <li>• Provide alternative forms of communication for expressing pain (e.g., adaptive technology programs, visual pain scales)</li> </ul>

### Treatment of SIB depends on the severity of the behavior

- Ignoring low-level SIB (i.e., minimal harm), combined with teaching replacement behaviors and praising expected behaviors is often very effective
- SIB with serious risk of physical harm (e.g., forceful head-banging, use of sharp objects) cannot be ignored. Intervention may include:
  - Medication (often atypical antipsychotics)
  - Physical protection (transport to a safe space, removal of harmful objects, blocking pads on walls)
  - Hospitalization

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## Suicidality in IDD

### Screening for suicidality in children with I/DD

- Greater risk in children with higher cognitive ability and greater awareness of social challenges
- Most self-injury does not indicate suicidal intent, but it does occur. Do not assume that cognitive disability = lack of suicidality
- Screen for suicidal thoughts whenever depression or SI is suspected.
- \*Asking about suicidal ideation does not increase risk of suicidality.\*
  - Use developmentally appropriate language (e.g., "Have you ever felt so bad that you didn't want to live anymore?")
  - May help to use number or picture scales to rate these feelings
  - Enlist the help of parents if child has difficulty with self-report

### Responding to suicidality in children with I/DD

- As with other children, do a careful risk assessment
  - Are thoughts of suicide passive and vague, or is there plan or intent?
  - Remove access to harmful objects (medications, sharp knives, firearms)
  - Make a plan for close supervision and contact with MH professionals
  - Refer to emergency department as needed for serious concerns
- May require medication, or adjustment to existing medications.
  - Ideally, refer to a psychiatrist with expertise in I/DD.
- Identify and address stressors (e.g., bullying, academic problems, family conflict, substance abuse)



### Behavior Management for co-morbid MH/IDD

### Behavior Management for co-morbid MH/IDD

- Individuals with MH/IDD have a high rate of behavioral challenges
- Behavior plans are developed to respond to inappropriate behaviors and to teach adaptive skills.
- **Evidence-based treatment** approaches are those that have been empirically tested and are proven effective
- It is considered best practice to use evidence-based treatments developed for those with IDD to treat behavior disruptions, teach appropriate behavior, and teach independence skills in individuals with MH/IDD

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### Individuals with MH/IDD show increased risk for

- behavior challenges
- self-injury (head banging, skin picking)
- repetitive behavior patterns
- repetitive speech patterns
- noncompliance
- aggression
- communication impairments
- complex sensory needs
- emotional dysregulation
- confusion

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### Intervention is warranted when behaviors are

- harmful to the self or others
- unsafe or destructive
- distressing to the individual/family/staff
- disruptive of learning
- disruptive of social functioning
- hindering participation in daily living or occupational activities

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### Functional Behavior Analysis

- describe the interfering or problem behavior
- identify antecedent and consequence events
- consider the function of the behavior
- design intervention to replace behavior with a more adaptive behavior serving a similar function
- often most helpful with considering function of
 

self-injury	elopement
aggression towards others	destructive behaviors
- **data collection** is an important part of the FBA

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## Developing a Plan

### Behavior Intervention Plan

- Addressing the antecedents
- Changing the consequences
- Teaching replacement behaviors that meets the function but is more acceptable

### Changes to the Environment

- Changing the physical environment
- Changes in instruction
- Changes in the social environment



## \*\*Positive Strategies for Supporting Behavior Improvement\*\*

- Espouse a mindset that is preventative rather than in response to behavior
- Set expectations by saying what you want to see instead of what not to do

"I want to see walking feet in the store" instead of "No running in the store"

- Praise and encouragement should be frequent
- Praise should be specific, not generic

"Great job putting away your clothes" instead of "Good job"

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## Positive Strategies (continued)

- Validate emotions and/or give language to teach self expression
  - "I know you wanted to walk to the park and now you are feeling angry that it is raining."
- Ignore low level behaviors
  - whining, fidgeting, noises
- Differentiate attention toward positive or prosocial behaviors
- Modeling—Demonstrate desired behavior

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## Positive Strategies (continued)

- Visual aids, photographs or video models are great ways to teach/show expected behavior
- Provide opportunities for success
- Schedule breaks throughout the day for preferred activities
- Allow individual to request a break when needed
  - for less-verbal individuals make a visual break card available

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## Positive Strategies (continued)

- Provide opportunities for choice making (available choices can be controlled)
- Establish a reward system consistent with the individual's level of understanding
- Allow time to do their preference
  - repetitive behavior, discussion of restricted interest, playing/looking at restricted interests
  - Does this need to be scheduled?


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## Response Interruption/Redirection

- Use of a prompt, comment, or distractors when an unwanted behavior is occurring to divert attention away from the behavior
- Most often used to address behaviors that are repetitive, stereotypical, and/or self-injurious and/or thoughts that are perseverative
- Interrupt behavior and direct to more appropriate, alternative behavior
  - typically used for behaviors that are not maintained by attention or escape
  - such behaviors are often maintained by sensory reinforcement

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 **Visual Supports**

- Visual cues about one's activity, routine, or expectation
- Can be quite varied in form and function
- Used to
  - organize the environment
  - establish expectations around activities
    - schedules                      instructions
    - work systems                video modeling
  - provides reminders
    - timers                          activities to chose from
    - appropriate behavior      when something is complete

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**Cognitive-Behavioral Interventions**

Cognitive-behavioral interventions:


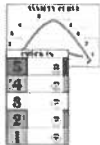
- Evidence-based practice for treating anxiety and mood-related concerns
- Can be adapted for individuals with developmental disabilities, such as ASD
- Better suited for individuals with well developed cognitive reasoning skills

**Facing Your Fears** (Reaven et al., 2012):

- Group cognitive-behavioral intervention
- Focuses on emotion education, coping skills, and exposure therapy
- Parent training component

**Other support tools:**

- Incredible 5-Point Scale (Buron et al., 2003)
- Zones of Regulation (Kuypers, 2011)

Source: Wood et al. (2009); Storch et al. (2013)

**Bibliography**

Borue et al. (2016) Longitudinal Course of Bipolar Disorder in Youth With High-Functioning Autism Spectrum Disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 55(12):1064-1072.

Charlton MK, Clithernes M, Tallant M, Taverne B, Tishelman A. (2004) Facts on traumatic stress and children with developmental disabilities: from the National Child Traumatic Stress Network Adapted Trauma Treatment Standards Work Group, Subgroup on Developmental Disability.

Chiholm K, et al. (2015) The association between autism and schizophrenia spectrum disorders: A review of eight alternate models of co-occurrence. *Neuroscience and Biobehavioral Reviews* 55: 173-183.

Cochran DK, et al. (2013) "Autism-plus" spectrum disorders: Intersection with psychosis and the schizophrenia spectrum. *Child Adolescent Psychiatric Clin N Am* 22: 609-627.

DSM-5 American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders*. Arlington: American Psychiatric Publishing.

Emerson, E & Hutton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry*, 191, 493-499.

Fletcher, R. J., Baker, D., St Croix, J., & Cheplie, M. (2015). *Mental health approaches to Intellectual/developmental disability: A resource for trainers*. Kingston, NY: NAAD Press.

Fletcher, R., Luszczek, E., Szymanski, C., & Frit, M. (2007). Intellectual Disabilities. In R. Fletcher, L. Luszczek, C. Szymanski, & M. Frit (Eds.), *Diagnostic Manual-Intellectual Disability: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disabilities*. (pp. 63-68). New York, NY: American Psychiatric Association

**Bibliography**

Munk, K. (2016) The co-occurrence of mental disorders in children and adolescents with intellectual disability/Intellectual developmental disorder. *Neurodevelopmental Disorders*, 29(2): 95-102.

Ko, SJ, Pynoos, RS, Griffin, D, Vonderbrink, D & NCTSN Trauma & IDD Expert Panel (2015). *The road to recovery: Supporting children with intellectual and developmental disabilities who have experienced trauma*. Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.

Kuypers, L. M., & Winner, M. G. (2011). The zones of regulation: A curriculum designed to foster self-regulation and emotional control. Think Social Publishing, incorporated.

Leeb, R.T., Bisho, R.H., Merrick, M.T., & Armour, B.S. (2012). Does childhood disability increase risk for child abuse and neglect? *Journal of Mental Health Research in Intellectual Disabilities*, 5.

Selten JP et al. (2015) Risks for Nonaffective Psychotic Disorder and Bipolar Disorder in Young People With Autism Spectrum Disorder: A Population-Based Study. *JAMA Psychiatry*, 72(5):483-488.

Skokauskas, N., Ford, T. (2015) Overlap between Autism Spectrum Disorder and Bipolar Affective Disorder. *Psychopathology*, 48 (4): 209-216.

*The Road to Recovery: Supporting Children with Intellectual and Developmental Disabilities Who Have Experienced Trauma Toolkit*. National Center for Child Traumatic Stress, 2015.

Turk, J., Robbins, J., & Woodhead M. (2005) Post-traumatic stress disorder in young people with intellectual disability. *Journal of Intellectual Disability Research*, 49:11, 872-875.