IDENTIFYING AND ADDRESSING MENTAL HEALTH NEEDS IN CHILDREN AND ADOLESCENTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (IDD)

November 3rd, 2021

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OBJECTIVES

1. Identify signs of emerging or ongoing mental health challenges.
2. Learn strategies and supports to manage mental health challenges.
3. Recognize when to refer to a mental health provider.
DEFINING IDD:
Disorders that emerge within the developmental period (<18 yo) and that uniquely affect the trajectory of an individual’s physical, intellectual, and/or emotional development.

- Intellectual disability: impairment in intellectual functioning and adaptive behavior
- Other developmental disabilities: autism spectrum disorder, ADHD, learning disorders, cerebral palsy, Down Syndrome, Fragile X Syndrome, fetal alcohol spectrum disorder
At least 1/3 of individuals with IDD have significant behavioral or mental health challenges requiring mental health services. More children and teens with IDD are diagnosed with mental health conditions as compared to those without disabilities. Supporting mental health is an essential part of supporting individuals with IDD.

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4-5x more children and teens with IDD are diagnosed with mental health conditions as compared to those without disabilities.
IMPACT OF COVID

- Increased unpredictability and social isolation
- Financial stress
- Higher caregiver burnout
- Decreased access to school-based and in-person community services
- 20% decline in early intervention referrals from March 2020 to January 2021
  - Significant impact on most vulnerable families: those from low-income neighborhoods, who had a baby in a neonatal intensive-care unit, or who speak a language other than English or Spanish

**NEWS › HEALTH › News**

**Fewer Colorado kids getting early help for developmental delays**

Pandemic, rule change triggered by state budget cuts both play roles
Social Determinants of Mental Health

- Poor Mental Health
  - Reduced choice
  - Behavioural risk
  - Physical stress
  - Psychological stress

- Low housing quality
- Adverse built environment
- Interaction with crime
- Childhood maltreatment
- Air pollution
- Unemployment
- Bad healthcare
- Discrimination
- Education inequality
- Income inequality
- Poor diet

Unfair opportunity distribution

Public Policy

Social norms

(Compton & Shim, 2019)
THE MOST COMMON MENTAL HEALTH DIAGNOSES:

- Anxiety
- Attention Deficit/Hyperactivity Disorder (ADHD)
- Depression
### What Makes the IDD Population Vulnerable to Mental Health Challenges?

- Language or communication difficulties
- Limited coping or problem solving skills
- Limited social supports or social rejection/stigmatization
- Mismatch between environment and strengths
WHY MIGHT MENTAL HEALTH SYMPTOMS BE MISSED?

- Diagnostic overshadowing
- Symptom overlap
- Unique symptom presentation
- Impact of individual factors, such as gender and intellectual ability
- Limited ability to communicate emotions or challenges
For example...

**Autism**
- Repetitive questions about a topic of interest
- Difficulty with transitions and unexpected changes
- Challenges with social relationships
- Sensory sensitivities

**Anxiety Disorders**
- Repetitive reassurance seeking
- Avoidance of situations accompanied by fearfulness
- Worry about social rejection or negative evaluation
- Anxious anticipation of a stimulus
MANY PEOPLE EXPERIENCE WORRY, SADNESS, AND OTHER PROBLEMS. THESE ARE NORMATIVE HUMAN EXPERIENCES!

Most of the time, these feelings come and go. When symptoms are excessive and persistent, and interfere with daily life, it might be time to speak to a mental health professional.
WHAT TO LOOK FOR

- Significant change in behavior
- Increase in intensity of frequency of behavioral outbursts
- Previously effective strategies no longer work
- Symptoms cannot be explained by developmental differences
- Symptoms interfere with day-to-day functioning
- Symptoms are present across settings and persist for at least 2 weeks
- Family history of mental health diagnoses
- Avoidance of certain situations or refusal to do things
- Physical symptoms like shaking, stomachaches or headaches, or rapid heart rate
- Negative self-talk
- Needing lots of reassurance
- Unique worries like not having enough time to engage with an interest
- Anxiety around change, or anticipated change, in routine
Depression

- Feeling sad or down for most of the day for many days
- A loss of interest or enjoyment in things they used to like
- Changes in sleep or eating pattern
- Fatigue or loss of energy
- Decreased concentration, more so than usual
- Worsening school performance
- Irritability or becoming easily annoyed
- Increase in aggression or self-harm
- Self-deprecating statements
- Active or passive suicidal statements
• Lack of focus
• Hyperfixation and difficulty shifting attention
• Being easily distracted
• Disorganization
• Difficulty with planning and task initiation
• Fidgeting, trouble sitting still
• Interrupting or intruding on others
• Always "on the go"
• Attention and/or activity level inappropriate for developmental level
How to Screen for Mental Health Symptoms

• Interview caregivers
  ◦ Symptoms: onset, duration, frequency, intensity
  ◦ Additional factors: medical conditions, medications, sleep and appetite, external events
  ◦ Consider impact of COVID: family perspective, access to services

• Direct observation
• Administer appropriate screening tools
MENTAL HEALTH SCREENERS

- Anxiety: Screen for Child Anxiety Related Disorders, ADAA free screening tool
- Depression: PHQ-9 for Adolescents, CESD Depression Scale for Children
- ADHD: NICHQ Vanderbilt
FIRST STEPS TO TRY AT HOME OR IN SCHOOL
**ANXIETY & DEPRESSION: SELF-CARE STRATEGIES**

- Establish regular self-care routines
- Incorporate regular exercise and physical activity
- Stay engaged with enjoyable activities
- Maintain a regular sleep schedule
Calm Body

• Squeeze a stress ball
• Deep breathing (e.g., smell the flower, blow the candle)
• Exercise
• Sensory activity or fidget toy
• Deep pressure

Calm Mind

• Use helpful thoughts and positive self-talk
• Fight fears with facts
• Practice mindfulness
• Think about a favorite activity or interest
• Recite a calming mantra
ANXIETY & DEPRESSION: BEHAVIORAL STRATEGIES FOR INDIVIDUALS WITH IDD

- Provide additional support
- Manage expectations and consider developmental level
- Prepare for new situations using visual supports
- Incorporate behavioral strategies consistently as part of effective teaching/interaction
First bathroom, then legos

Sally’s Morning Schedule
- Breakfast
- Yoga
- Math at table
- Playtime
- Lunch
ANXIETY AND DEPRESSION: CBT STRATEGIES

- Validate and label feelings
- Practice positive self-talk
- Counter negative thoughts
- Encourage and reward brave behavior to face fears
- Use visuals to support understanding of and communication about emotions
Size of the Problem

Remember the size of your reaction has to match the size of the problem!

How big do others see the problem?

How big should your reaction be?

Visual adapted by Leah Kupers, Donna Brittain and Jill Kuzma for The ZONES of Regulation® from the original work of Westen's Think Social (2005), pages 44-45, www.socialthinking.com, and Burrell and Curtis' The Incredible 5-Point Scale (2008), www.5pointscale.com

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MANAGING ADHD: BEHAVIORAL STRATEGIES

- Schedule movement breaks throughout the day
- Build in stimulation with fidget toys or modified seating
- Limit distractions
- Use a reward or behavioral reinforcement system
- Break large tasks into smaller chunks
- Create clear organization systems
- Use visual supports to track tasks and shift between activities
Creating and following a schedule provides predictability and a sense of control – particularly during the uncertainty of COVID-19!

- Schedule self-care and high interest activities throughout the day
- Identify COVID-safe forms of social connection
- If the news feels overwhelming, schedule "worry time" once per day to watch/read the news
MENTAL HEALTH SYMPTOMS CAN ALSO PRESENT AS "CHALLENGING BEHAVIORS".

Without appropriate intervention and support, these behaviors can have a significant impact on quality of life, negatively impact social relationships, decrease educational opportunities, and increase risk for injury and abuse.
FUNCTIONS OF BEHAVIOR

- Communication
- Escape
- Social Attention
- Access to Tangibles
- Sensory stimulation
FUNCTIONAL BEHAVIORAL ASSESSMENT

• 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 helpful with considering function of: self-injury, elopement, aggression towards others, destructive behaviors
• Data collection is an important part of the FBA
ABC Analysis

Name: George

Description of behavior(s) of interest: humming loudly, telling an inappropriate joke, putting head on desk, refusal to participate, throwing books.

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Antecedent</th>
<th>Behavior</th>
<th>Consequence</th>
<th>Possible Function</th>
</tr>
</thead>
<tbody>
<tr>
<td>2/7/99</td>
<td>9:40am</td>
<td>Teacher announces it is time for reading</td>
<td>Tells inappropriate joke</td>
<td>Peers laugh, class disrupted</td>
<td>Escape/Atten.</td>
</tr>
<tr>
<td>2/7/99</td>
<td>9:45am</td>
<td>Teacher calls on George to read first</td>
<td>Throws book</td>
<td>Sent to office</td>
<td>Escape</td>
</tr>
<tr>
<td>2/8/99</td>
<td>9:35am</td>
<td>Teacher asks George to pay attention</td>
<td>George crouches down so he can't see</td>
<td>George can't see instruction</td>
<td>Escape</td>
</tr>
<tr>
<td>2/8/99</td>
<td>9:40am</td>
<td>Teacher instructs class to move into reading groups</td>
<td>George sighs, puts head on desk</td>
<td>George doesn't join his group</td>
<td>Escape</td>
</tr>
<tr>
<td>2/8/99</td>
<td>9:42am</td>
<td>Teacher asks George to move to his reading group</td>
<td>George slams his book shut</td>
<td>George's teacher warns him not to throw book</td>
<td>Escape</td>
</tr>
<tr>
<td>2/8/99</td>
<td>9:50am</td>
<td>Teacher says go to your group</td>
<td>George throws his book and walks out of the class towards the principal's office</td>
<td>Avoids reading group</td>
<td>Escape</td>
</tr>
</tbody>
</table>
POSITIVE BEHAVIORAL APPROACHES

- Take a proactive rather than reactive approach
- Set expectations by saying what you want to see instead of what not to do
  - ✓ "Please listen quietly."
  - ✗ "Don’t interrupt!"
- Praise and encouragement should be frequent
- Praise should be specific, not generic
  - ✓ “Great job asking for help!”
  - ✗ “Good job.”
• Validate emotions and give tools to teach self-expression
  ○ "I know reading is tough for you and you seem really frustrated right now."
• Ignore low level behaviors when possible
• Differentiate attention toward positive or prosocial behaviors
• In times of upset: reduce language, pair language with visuals support, provide visual means to communicate needs or feelings
POSITIVE BEHAVIORAL APPROACHES

- Use visuals to support communication
- Provide opportunities for success
- Incorporate choices when possible
- Schedule time for breaks and preferred activities
  - Establish locations and regular times to practice calm down and coping routines
WHEN TO REFER TO A MENTAL HEALTH PROFESSIONAL?

- If a crisis arises, such as a suicide attempt, active suicidal ideation, self-injury, elopement, dangerous impulsivity, seek professional intervention immediately.
- When anxiety and sadness are excessive, persistent, and interfere with daily life.
- If you notice significant changes in mood or behavior, for example:
  - Changes in sleep or appetite
  - Withdrawal or frequent tearfulness
  - Increased aggression or impulsivity
- Whenever it would be helpful to have professional support - you don't have to wait for crises to occur!
WHERE TO REFER?

- Mental health providers who are able to tailor treatment to the strengths and needs of the individual using evidence-based approaches
- Contact school mental health team
RESOURCES: MENTAL HEALTH

- Contact your local mental health center
- Use the Association for Behavioral and Cognitive Therapies "Find a CBT Therapist" Tool: findcbt.org/FAT/
- Colorado Crisis Services - https://coloradocrisisservices.org/
- JFK Partners webinars - https://medschool.cuanschutz.edu/jfk-partners/education-training/archived-webinars
- Facing Your Fears ID study (contact FYFstudy@ucdenver.edu)
- Connect with JFK Partners about school-based Facing Your Fears intervention (judy.reaven@cuanschutz.edu)
RESOURCES: COVID-19 SUPPORT

- Anxiety and Autism: Family-based strategies for returning to school after shelter in place, from the UCDavis Mind Institute: https://www.youtube.com/watch?v=CvI26zHncZU
- Online Learning Resources from AFIRM: https://afirm.fpg.unc.edu/online-learning-resources?fbclid=IwAR3_W6-ZMnIX9itKL4pIQ3nOJvT_3MMwcB-_ujO30Eg62RItgExXVtn3eU
- Check out the JFK Partners webpage for more resources, coming soon to https://medschool.cuanschutz.edu/jfk-partners
RESOURCES: CAREGIVER SUPPORT

• The PEAK Parent Center provides a variety of resources for parents and caregivers of children with disabilities (1-800-284-0251; www.peakparent.org).
• The Living Spectrum parent support groups (thelivingspectrum.org/index.php)
• El Grupo Vida is a network of Hispanic/Latino parents that provide support for people with disabilities or special needs, their parents, family and guardians. elgrupovida.org; 303-355-9875.)
THANK YOU FOR LISTENING!

Feel free to send any questions to rachel.sandercock@cuanschutz.edu.