PPRACTICE Makes Perfect: Navigating skills for youth with autism and intellectual and developmental disabilities

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“Abuse of people with disabilities is a hidden epidemic with a huge number of invisible victims”
Jim Stream
www.disabilityandabuse.org
Merging Fields of Knowledge

Goals for today:

1. Learn about prevalence and frequency of trauma with youth with ASD & IDD
2. Challenge common myths and misconceptions
3. Gain skills to adapt Assessments of PTSD in youth with ASD & IDD
4. Gain skills to adapt PRACTICE components to meet needs of this special population
What does IDD/ASD Encompass?

- Developmental Disability
  - Under this very broad heading, in this presentation, we will mean
    - Intellectual Disability (the current name for what was once called "Mental Retardation")
    - Autism Spectrum Disorders (ASD)
    - Delays due to environmental factors (such as FAS or TBI)
    - Other developmental delays (e.g., genetic conditions, learning disability, etc.)
  - All developmental disabilities present differently- even within the same diagnosis

What we know

Youth with Intellectual and Developmental Disabilities (IDD) are at higher risk for experiencing almost every type of trauma, including:

- Physical Abuse
- Witnessing Domestic Violence
- Sexual Abuse
- Neglect and emotional abuse
- Psychological distress to medical procedures

44% of victims with IDD had a relationship with their abuser directly related to their disability (Davis, 2004)
Common Concerns and Assumptions

- Youth with IDD are not impacted by their trauma/do not understand the impact
- Youth with IDD cannot learn
- Youth with IDD cannot participate in psychotherapy
- Mental health providers need specialized training to work with youth with IDD
- Providers feel incompetent with working with youth with IDD

Potential Pathways of Maltreatment & Developmental Disability
Impact on Providers

- Positive impact from working with a special population
- Positive and negative emotional impacts
- Feelings of ineffectiveness/incompetence
- Frustration, feeling not making progress
- The “ah-ha” moment when things click

Common Difficulties for youth with ASD/IDD

Describe your perfect date.

That’s a tough one. I’d have to say April 25th. Because it’s not too hot and not too cold. All you need is a light jacket.
Common difficulties for youth with ASD/IDD

- Difficulty with concepts of time, volume, “amounts”
- Difficulty with perspective taking
- Difficulty identifying emotions in self and others
- Difficulty discerning emotions from one another
- Impulse control/decision-making
- Physical limitations
- Difficulty reading
- Discrepancy between developmental age and chronological age
- Discrepancy between developmental age across different tasks and settings
- High focus/interest in only one subject matter - difficulty engaging in anything else
- Mute or poor receptive and expressive language skills

This list is not final!

Adolescence²
Adolescent + Autism = ?<Development, Knowledge, Skill>?
Addressing Challenges and Trauma

Common Themes to Remember:

- Meet child at their “cognitive age”
- Pace (e.g., slow down speech)
- Complexity (e.g., use simple language)
- Timing (e.g., present one concept at a time)
- Sequencing (e.g., rearrange questions to build on strengths)
- Patience and Repetition
- Repetition
- At-home practice
  - importance of parents, friends, community members, etc
- Increasing structure and behavioral reinforcement in therapy
  - Visual schedules
  - Clear behavior management system
  - Clear Goals for each session
Assessing Trauma in Youth with IDD

- Screening highly important
  - Trauma is typically underreported due to youth’s difficulty with communication, misunderstanding of what is acceptable and appropriate behavior, and increased complicity with authority figures

- Similar to the general population, not every child with trauma histories develop PTSD and/or require trauma-focused treatment

Types of Maltreatment

- Physical Abuse
  - I feel and react to pain

- Emotional Abuse
  - Just because I look like I’m not listening, doesn’t mean I can’t hear
  - Just because I don’t hug, doesn’t mean I don’t like you around

- Sexual Abuse
  - I don’t understand danger

- Neglect
  - I’m trying, but it is hard to communicate and do everyday things other people do. Please care for me.
PPRATICE, PPRRATICE, PPRRATICE

- Parenting Skills
- Gradual Exposure
- Enhancing safety

Time: 12-16 sessions

Stabilization Phase
- Psychoeducation
- Relaxation
- Affective Modulation
- Cognitive Coping

Trauma Narrative Phase
- Trauma Narrative and Processing

Integration/Consolidation Phase
- In vivo Conjoint sessions
- Enhancing safety

Flexibility while Maintaining Fidelity

- Anticipate extended treatment time to 18-24 sessions
- Move Enhancing Safety to the beginning and continue throughout treatment
  - Youth with IDD typically:
    - Struggle to identify unsafe or risky situations
    - Struggle to communicate needs and concerns
    - Are at high risk for continued ongoing stressors (i.e., appointments with caretakers or medical professionals, negative peer interactions, etc.)
Modified TF-CBT Model

- Psychoeducation
- Relaxation
- Affective Modulation
- Cognitive Coping

Stabilization Phase

Trauma Narrative Phase

Integration/Consolidation Phase

In vivo Conjoint sessions

Gradual Exposure

Parenting Skills

Time: 18-24 sessions

Enhancing Safety

- Stabilization of placement
- External environment, structure, stability
- Habit reversal
- Okay Touch vs. Not okay Touch
- Private Part Rules
- No-Go-Tell/ROAR

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Parenting, Parenting, Parenting

Review of TF-CBT Parenting Goals

- Normalization or response to trauma
- Skills building
  - Response to problematic behavior
  - Praise
  - Selective attention
  - Timeout-outs
  - Contingency reinforcement
Challenges for Parents of Youth with IDD/ASD

- Stressed and overwhelmed
  - Supervision demands
  - Need for education and preparation for raising a child with DD
  - Lack services for children with DD
  - Children need enhanced skills to respond to reinforcement and discipline

Getting Families Back to Normal

- Promote a “balance”

![Balance Scale Diagram]

- Nurturing Interactions
  - How to Show Love, Safety, Security, and Increase Positive Behavior
- Appropriate Limits
  - How to Respond to Child’s Behavior
Overarching message to parents

- Antecedents ➔ Behavior ➔ Consequences
  - Children do things for a reason (If it worked one time, maybe it will work again)
  - Children thrive on structure and routine that is consistent and predictable
  - Caregivers can do amazing things by applying prevention (antecedents) strategies and responding differently (consequences) to both positive and negative behavior

- Children do things to:
  - Get attention
  - Gain something
  - To get out of things
  - Because they like the way it makes them feel

- Behavior can change! And small changes can make a huge difference!

Questions to ask yourself in Parenting

- Have I used the parents expertise for their child?
- Am I helping the family with structure and routine?
- Am I helping the parent come up with effective reinforcement?
- Am I being realistic with my recommendations?
- Am I connecting the family with community support?
- Do I need to shift focus from behavioral problems to trauma reaction or vice versa?
- I am working with the family team to understand medication management?
- Have I reached out to my own colleagues for support and resources?
Relaxation

General Technique Adjustments

- Simplification in communicating
- Smaller portions of information at a time
- Repetition and multiple means of teaching information
- Multiple senses engaged at each component
- Structure, behavior management
- Patience and rolling with roadblocks

The child with autism is like a Mac in PC world. He's hard-wired differently. Not incorrectly—just differently. Teach him in a manner meaningful to him.

Ellen Notbohm
Challenges in relaxation with IDD/ASD

- Higher baseline anxiety and agitation (fixation/rigidity)
- Difficulty remembering and generalizing relaxation strategies
- Issues with sensory integration and sensitivity
- Potential for higher caregiver stress

“It may not look the same”

Relaxation

- Break it down!
- Incorporate visualization and guided imagery
- Use physical prompts and modeling
- Incorporate parents, siblings, and teachers
- Repetition, repetition, repetition
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Relaxation Strategies

Heavy Hitters:
- Deep Breathing
- Progressive Muscle Relaxation
- Grounding

Questions to ask yourself:
- Do they keep the child’s attention?
- What are the child’s interests and how can I include them?
Grounding

- If overwhelmed by sensory feelings develop a toolkit with items they find soothing and can use for grounding (bubble wrap, sandpaper, cotton, felt, playdough, water and sand)
- When a child experiences a trigger that is overwhelming we don’t want child to only rely on a person to calm down
- One example from developers is “pocket pat” a felt cut out of the person that served to help ground the child

Progressive Muscle Relaxation

1. Sit on a chair...
2. ‘Scrunch’ up your face...
3. Tense your arms... then relax... then relax
4. Tense up your shoulders and chest... then... relax... then
5. Tense up your legs...
6. Breathe in relaxation...

Calm Counter is a visual and audio tool to help people calm down when they are angry or anxious
Youth Coping Resources

Breathe, Think, Do

http://youth.anxietybc.com


Affect Identification
Challenges in Affect

- “This kid has autism, so he’ll never be able to get emotions. We can skip this section, right?”

Challenges to Affect

- Children with IDD/ASD may have:
  - Difficulty identifying emotions in self and others
  - Difficulty expressing emotions by facial gestures and/or verbally
  - Sensory sensitivity
  - Impulsivity
  - Agitation
  - Heightened anxiety
  - Greater behavioral challenges
Affect Identification and Rating

- Reduce number of feelings to use
- Master identification of those feelings
- Attempt teaching in multiple ways and modalities
  - Connect faces to their interests or to real life pictures
  - Practice making faces in mirror
  - Prompt for creative ways to describe and visualize feelings rating?
  - Movie / TV Show / Video Clips

Cognitive Coping
Challenges to Cognitive Coping

- May have difficulty with
  - Abstract thinking
  - Sequencing events
  - Task breakdown
  - Ambiguity

Cognitive Coping

- Help children to sequence behaviors
- Use of Social Stories and visual aids
Cognitive Coping

- Spend time explaining thoughts
- Make it interactive
- Use play
- Use art/visuals
- Incorporate interests

Trauma Narration
Trauma Narration

“My kid says he/she doesn’t remember what happened”

- Impaired cognitive functioning does NOT mean impaired memory
  - If there’s a memory concern- can you check child’s recent neurological testing or request a neuropsychological evaluation at the beginning of treatment?

Trauma Narration

- **Tip #1: Set your baseline**
  - Start with Timeline
  - Add a LOT of visuals for your kids
  - Ex: Visual Calendar (or turn the room into a “year”)

- **Tip #2: Keep it fun and active**
  - If possible, use stations
  - “Scavenger Hunt” for questions about the trauma
  - This might be a great place for a Pictorial Narrative
Trauma Narration

Tip #3: Structure. Is. Your. Friend

- If something is not working, just add (more) structure
- "He wouldn't talk about his trauma"
  - Did you do a timeline?
    - "Ya"
    - Have you tried a question and answer game?
    - Series of questions about the trauma (e.g., "What room did it happen in?")
    - "Ya"
      - Have you done the fill in the blank method?
      - "I was ____ years old when my dad died"

Tip #4: Add behavioral reinforcers

- Ex: For the fill in the blank method, you put points on each blank and they get a prize for accumulation of points at the end of session
- Also, general behavioral reinforcers
  - ONLY reward effort and on task behavior, NOT content of answers
- Always keep in mind A \(\rightarrow\) B \(\rightarrow\) C
Trauma Narration

• Last tip
  ○ Remember your principles of a good TN
  ○ 1: Specificity and Coherency
  ○ 2: Did you hit as many parts of the triangle as possible?
  ○ 3: Did you hit the 3 Goals of TN (desensitize, red flag cog distortions, make meaning)?
  ○ 4: Did you do a Conjoint Sharing after the TN was completed?

Cognitive Processing
Cognitive Processing

- Create visuals for cognitive triangle and unhelpful thought’s impacts on child’s feelings and behavior

- How do we help make meaning and direction for kids
  - Socratic questioning
  - “Playing dumb”
  - Lists of evidence for and against

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Resources

- A Better Chance Clinic (ABC) - OUHSC
- Jumpstart Clinic - ADHD Testing
- JD McCarty - Norman, OK
- Sooner Success
  - Sibshops
- NCTSN Resources

“IF THEY CAN’T LEARN THE WAY WE TEACH, WE TEACH THE WAY THEY LEARN.”

DR. O. IVAR LOVAAS

Q&A