Addressing the Mental Health Needs of People with Intellectual and other Developmental Disabilities

DePelchin Trauma-Informed Care Conference
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Objectives:

- Recognize the current system limitations on mental health services for individuals with IDD
- Identify the challenges in diagnosing and treating individuals with co-occurring IDD and mental health conditions.
- Understand the impact of trauma on individuals with IDD
- Identify what needs to be done to create a trauma-informed system of treatment and supports for individuals with IDD.
What are we doing now?

- We frequently attribute behaviors to the disability.
- We often try to manage behaviors through some type of authority/control/compliance model.
- We focus on challenging behaviors and crisis intervention instead of the mental health and wellness of people with IDD.

Why is it that when your IQ is over 75 you have a “mental health condition” that need assessment and treatment, but if your IQ is low you have “behaviors” that need managing?
What mental health conditions do people with IDD experience?

The same mental health conditions as anyone else including depression, schizophrenia, bi-polar, anxiety, compulsive disorders, post-traumatic stress, etc., etc., etc.

They just experience these conditions at higher rates than the general population.
Challenges in assessing, diagnosing and treating mental illness in people with IDD

- Overshadowing
- Communication challenges
- Lack of expertise in both the mental health field and in the IDD field
- Extended time it takes to assess (requires talking to more than just the patient; must interview critical caregivers, family, etc.)
- Professional biases – belief that evidence-based mental health treatments don’t work on this population
- Mental health workforce shortage – especially expertise with people with IDD.
Challenges (continued)

- Lack of cross-agency coordination

- Treating the behavior instead of the underlying mental health or medical condition; ease of using medication

- Failure to address the impact of past trauma

- Lack of consideration of people with IDD in state mental health policy

*People with IDD deserve the same state-of-the-art mental health treatment as everyone else.*
Think about….

- Think about the last time you behaved badly...

- When you were behaving badly, were you doing it...
  1. To manipulate people and take advantage of the situation, or
  2. Were you responding emotionally to some situation or event?

- Why do we often assume people with IDD are trying to manipulate their environment and the people in it? Why do we often try to manipulate them to “behave appropriately?” Why do we not consider their emotional and psychological condition?

Why are we reducing people with disabilities to their behaviors?
The goal when treating mental illness should be recovery. If recovery is to be achieved, we must be sensitive to the potential for underlying mental health or medical conditions and not simply try to manipulate current behaviors.
Focus on Recovery

- The Substance Abuse and Mental Health Services Administration (SAMSHA) defines recovery as “A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential.” The mental health system in Texas is a recovery-based system. However, the principles of recovery have not been incorporated into our system of care for people with IDD. [http://www.samhsa.gov/newsroom/advisories/1112223420.aspx](http://www.samhsa.gov/newsroom/advisories/1112223420.aspx)

- We need to develop a recovery focused approach to care for people with co-occurring IDD and mental health conditions. We know that people living with mental illness can recover and people with IDD deserve that opportunity.
Ingredients Necessary for Recovery
(K. Harvey)

Perceived Safety

Empowerment ↔ Connection
What about trauma?

What is a traumatic event?

- Trauma comes in many forms. Traumatic experiences can include: abuse and/or neglect, witnessing violence, abandonment or the loss of a loved one, traumatic grief, bullying, a natural disaster or car accident, painful medical treatment, school violence and more.

- Trauma can be caused by the culmination of multiple events or can result after a single episode.

- Trauma can change an individual’s sense of safety and how they perceive the actions of others – even those trying to help them.

- Trauma can change how individuals perceive themselves.

- Trauma impacts development and mental wellness.
Why is this important to people with IDD and those supporting them?

- High rates of abuse including physical, sexual and emotional
- High rates of bullying
- Victims and/or witnesses of violent crimes
- Family stress can turn into family violence
- Institutionalization
- Abandonment and isolation
- Restraint and seclusion
Reaction to trauma or trauma triggers

- Symptoms of trauma can manifest in behaviors and unless caregivers and professionals know how to identify trauma in people, they may exacerbate the impact of past traumas or create new traumatic experiences.

- Trauma exposure can lead to long-term social, emotional, developmental, psychological, and physical health problems.
Impact of trauma exposure on children (NCTSN)

- The world is uncertain and unpredictable; creates problems with boundaries and distrust; can cause social isolation.
- Increases stress hormones changing the brain chemistry. Can cause hypersensitivity to physical touch. May cause unexplained physical health problems.
- Causes difficulty in regulating emotions, difficulty in describing feelings, wishes and desires to others.
- Creates feelings of detachment, withdrawal, amnesia-like state.
Impact on children (continued)

- Causes poor impulse control, self-destructive behavior, aggression, sleep disorders and eating disorders.
- Causes problems with focusing and completing tasks, difficulty with planning, learning difficulties and language development.
- Instills a lack of predictable sense of self, low self-esteem, shame and guilt.
- Causes problems with emotional regulation and over-controlled or under-controlled behavior.
The science of trauma

- When trauma occurs or past traumas are triggered, the brain reverts to its reptilian stage of survival.
  - Fight
  - Flight
  - Freeze

- Person perceives that he/she is in danger.

- Rational mind shuts down and reverts to survival mode.

- This is not a teachable moment! Especially true for children with IDD.
The Behavioral Pyramid
(K. Harvey)

Behavioral Issues:
- Emotions Expressed
- Often Rooted in Trauma

When we only address the behavior, we miss the true cause and root of difficulties. (K. Harvey)
What is trauma-informed care?

- Recognizes the impact of trauma on an individual’s development, behavior, mental and physical well-being.
- Recognizes the need for people to feel safe.
- Recognizes the impact of trauma on the caregivers.
- Often requires a re-direction of our thinking.

Coming soon! Training Toolkit for Trauma-Informed Care for Children with Intellectual/Developmental Disabilities developed by the National Child Traumatic Stress Network in partnership with the Hogg Foundation for Mental Health.
Examples of trauma-focused treatment

- **Trauma-Focused Cognitive Behavioral Therapy** is a short-term (12-16 weeks) treatment that teaches coping skills to children (6 years and older), youth and families helping them tell the story of the trauma they’ve experienced. Research studies consistently show a reduction in trauma symptoms for children treated with TF-CBT.

- **Child Parent Psychotherapy (CPP)** for young children (birth to 6) and their caregivers is an evidence-based treatment that addresses the attachment between child and parent, while working toward understanding and healing trauma.

- **Eye Movement Desensitization and Reprocessing (EMDR)** is a psychotherapy treatment that was originally designed to alleviate the distress associated with traumatic memories (Shapiro, 1989a, 1989b). Shapiro’s (2001) Adaptive Information Processing model posits that EMDR facilitates the accessing and processing of traumatic memories to bring these to an adaptive resolution.
The importance of Positive Identity Development

- Too often people with disabilities identify themselves as the person that “can’t.” “I can’t read.” “I can’t drive.” “I can’t take care of myself.” “I can’t go to college.”

- Many times the inner dialogue is even worse. People with IDD often identify themselves as being “bad.” “I get in trouble.” “I have behaviors.” “I need a behavior management plan.” “I have to be segregated.” “I’m not like the other kids.”

- People living with IDD can blame themselves for the abuse they experience.

- We need to change the way individuals with IDD perceive themselves.

*Positive Identity Development*, Karyn Harvey, Ph.D.
What’s being done in Texas?

- Trauma training is required in Texas child welfare system.
- Trauma training is required in juvenile justice system.
- What about the IDD world? *Trauma training has not been required for providers of IDD services...until now, and it’s still very limited.*
  - **HB 2789 (Raymond)** requires TIC training to be part of the initial orientation training for all employees at SSLCs and ICFs.

*It’s a start, but MUCH more is needed...we need a culture shift.*
What needs to be done in Texas?

- **Cross-agency collaboration** – DSHS and DADS must work more closely to identify the mental health needs of those with IDD and take joint responsibility for meeting those needs.
  - Create a cross-agency mental health unit/division for people with IDD. This division should build capacity for high quality standards, prevention, treatment and crisis supports and services including crisis intervention teams.
  - Recognize that substantial improvement is needed.
  - Prioritize the development of expertise and capacity across agencies.
  - Promote the use of non-pharmacological treatment – psycho-social, behavioral, and cognitive therapies.
  - Increase expectations that people with IDD will receive quality mental health services by developing standards of care in policies and practices that are recovery-based.
  - Develop a guide for providers and caregivers to provide a framework to improve access to quality mental health services for people with IDD.
What needs to be done in Texas?

- **Crisis intervention programs**
  - **Crisis Response Teams** – Crisis response teams that currently exist to support individuals experiencing a mental health crisis should be trained to provide crisis intervention to people with intellectual disabilities. Additionally, specialized crisis teams should be developed in each region to provide direct emergency services to people with IDD and to support other city and county crisis response teams.

- **Emergency respite options** – Currently, the only residential supports that exist for someone with IDD in crisis are hospitals, psychiatric hospitals or SSLCs – all of which are extremely costly. Making respite available to individuals in crisis allows opportunities for the individual, the family and the support team to stabilize, assess and develop a plan for recovery.
What needs to be done in Texas?

- Increase use of positive behavior supports and person-centered practices across systems; promote non-pharmacological interventions.

  Using positive behavior support strategies can effectively help to prevent crises from occurring and support individuals and families when crises do occur. Positive behavior support is a set of research-based strategies used to improve quality of life and decrease challenging behaviors. While there are many components to a comprehensive PBS system, supports are provided by making changes to the individual’s environment and teaching new skills.

Experts have argued that non-pharmacological - approaches to addressing challenging behaviors offer safer options for some individuals with IDD. Texas should:

- Ensure that non-pharmaceutical options for treatment are available.
- Monitor use of psychotropic medications being prescribed to individuals with IDD in state community and institutional programs.
What needs to be done in Texas?

- Look beyond psychopharmacology

  - Presence of challenging behaviors does not aid in identifying specific mental health conditions—Behavior has been shown to be a means of communicating distress, not a diagnostic characteristic. A 2012 study suggests that for individuals with limited communication skills, there are few ways to convey the pain or distress they are experiencing or to convey their frustration with their environment or aversive management techniques being used.

  - Perception that aggression and irritability can be treated effectively with drugs can discourage the need for a comprehensive evaluation.
What needs to be done in Texas?

- Develop a guide for providers modeled after *The Guide: Accessible Mental Health Services for People with an Intellectual Disability*, developed by the Department of Developmental Disability Neuropsychiatry at the University of South Wales in Sidney Australia.

- The Center for Autism and Related Disabilities at the University of South Florida has also developed an informative guide entitled *Autism & Mental Health Issues: A guidebook on mental health issues affecting individuals with Autism Spectrum Disorder*. This guide also provides an effective framework for building awareness and developing competencies relating to the mental health needs of people with IDD.

- The Hogg Foundation has partnered with the National Child Traumatic Stress Network for the development of a toolkit and curriculum to be used to provide training for trauma-informed care for children with IDD. The project includes statewide trainings that will be conducted by SafePlace.
What do WE need to do?

- Question current behavior management practices.
- Ask more questions, i.e., “have you considered depression, anxiety or trauma?” Force professionals to consider the possibility of underlying mental health or medical conditions.
- Stop looking for “what’s wrong” with people and start asking “what has happened to them,” and what that did to them.
- Move from a culture of control and compliance to one of respect and support.
- Look at current behavior management practices to determine if trauma is being exacerbated.
What else?

- Demand trauma-informed care and other evidence-based mental health treatment and practices including early identification and treatment.
- Start asking different questions – force others to think about the mental health of folks with IDD.
- Don’t settle for the status quo.
- Request better assessments.
- Demand better treatment.
Continuing the conversation...

- Look for opportunities to include the mental health needs of people with IDD in broader discussions – schools, waiver programs, parent trainings.

- It’s logical, don’t feel you have to be a clinician or scientist to make sense of this. Many of us have lived it.

- When filling out evaluations at trainings, workshops, etc., stress the need to include mental health for people with IDD in future programs and agendas.

- Talk to policy makers. Demand that the IDD population be included in other mental health systems planning.

*Now is the time!*
Hogg Foundation Efforts

- Two-year trauma-informed care training and technical assistance grant at two SSLCs to reduce the use of restraint.

- Partnership with the National Child Traumatic Stress Network to develop a training toolkit for trauma-informed care for children with IDD

- Funded a research project with EveryChild, Inc. to research and promote positive behavior supports

- Public policy priority
Additional Resources

- Karyn Harvey, Ph.D. -- *Positive Identify Development*

- Karyn Harvey, Ph.D. -- *Trauma-Informed Behavioral Interventions, What Works and What Doesn’t*


- NADD -- National Association of People with Developmental Disabilities and Mental Health Challenges, [www.nadd.org](http://www.nadd.org)

- Center for Disease Control and Prevention *Adverse Childhood Experiences (ACE) Study* [http://www.cdc.gov/ace/index.htm](http://www.cdc.gov/ace/index.htm)
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