Supporting Youth with Developmental Disabilities in Mental Health Crises

February 2025

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TEXAS COUNCIL for DEVELOPMENTAL DISABILITIES

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Agenda

- Introductions
- Background
- Historical Crisis Work
- Youth Crisis Outreach Teams (YCOT) Overview
- Best Practices
- Q & A
- Next Steps

Introduction

Our Unique Value: Intersection of Policy & Programs

STATE AND NATIONAL POLICY

Shape mental health policy

Extract lessons learned and proof points

Enact mental health policy

SOLUTIONS

Develop, implement, scale, and finance evidence-based solutions in local, state, and national systems

OUR VALUES

Collaboration and partnership | Data-driven and evidence-based | Innovation | Nonpartisanship | Stewardship

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Parent

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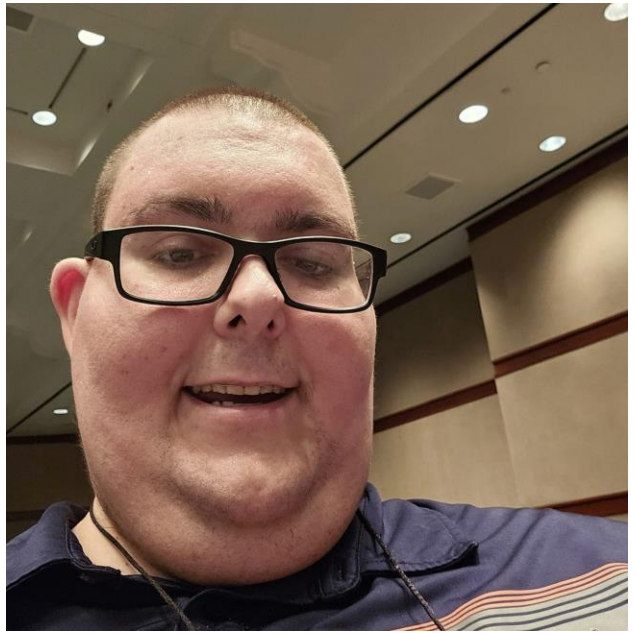

Jordan Smelley, MHPS

Certified People Planning Together Trainer

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Housekeeping

All participants will be muted.

We are recording this webinar.
The recording and slides will be sent out to all registrants.

Please put your questions in the Q&A feature at any time.

You will receive two surveys after this webinar.
We appreciate your time completing both.

Background

Developmental Disabilities (DD)

Developmental Disabilities and Mental Health Challenges

- An estimated **one-third** of people with a developmental disability also have mental health needs.[1]
- This population experiences traumatic events at higher rates than the general population.
- How people with DD experience (cope with and process) traumatic events may be different from the general population.[2]
- **Diagnostic overshadowing**, where a mental health challenge is inaccurately attributed to a person's developmental disability, is common.[3]
- There are an insufficient number of providers who are well trained in MH *and* DD.

Suicide Risk

Available Research

- There is limited research around risk of suicide in the broader DD population.
- Rates of suicidal ideation in youth with DD are between 22% and 60%.
- Overall, the limited data indicates higher rates of suicidal ideation and suicidal behaviors.
- There is some indication of "typical" and less typical attempt methods.[4]

Risk Factors

- Mood disorders
- Eating disturbances
- Significant familial loss
- Abuse
- Psychosocial stressors
- Regression in functional skill level or outward behaviors that differ from usual temperament [4]

Exclusion from Mental Health Services

Exclusion through Policies and Practices

- Based on diagnosis or IQ score
- Requirements around "functional abilities" or ability to carry out activities of daily living independently

Exclusion based on Provider Limitations

- Pointing to scope of practice concerns
- Limited expertise of staff
- Lack of appropriate resources

Unmet Mental Health Needs Can Increase Crisis in Youth with DD

Co-occurring mental health needs and DD can have a complex presentation.

There is a lack of evidence-based mental health interventions that have been tested and adapted for youth with DD and MH.

Historically, approaches have focused on observable behavior and not underlying emotional distress.

Youth with DD are more likely to be placed in seclusion/confinement and be restrained in schools.[5]

Historical Crisis Work

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Law Enforcement Involvement

- Historically, Law Enforcement (LE) were the only option to respond to people in crisis.
- Youth with DD are more likely to interact with LE.[6]
- Both members of the DD community AND LE have expressed dissatisfaction with these interactions.[6]
- LE have asserted need for more specialized training (but it is often not available).
- LE know they are not the most appropriate response for most mental health crises.
- Once LE are involved, they must follow specific protocols and procedures.

Crisis Response in Schools – Lived Experience Perspective

Seclusion and restraint

Eroded trust and feeling safe within systems

Impact on the entire family

Lack of options and limited access to resources

Impact on Workforce

"Challenging" behavior is associated with staff burnout

Staff burnout is linked to turnover

Ongoing workforce shortages compound staff stress

Emergency Room Involvement

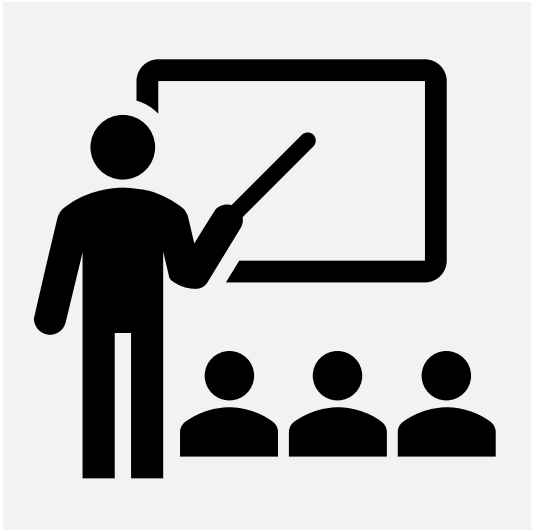
Youth with DD have higher rates of Emergency Department (ED) visits for mental health crises[7]

At the ED, youth with DD are more likely to:

- Stay for longer durations
- Experience seclusion and restraint[8]

Lessons Learned and Incorporating in Current Practice

Law Enforcement



Schools

Workforce

Emergency Room

Youth Crisis Outreach Teams (YCOT)

What is YCOT?

Urgent response

- Meet sense of urgency with urgency
- Prioritizes rapid, face-to-face response in the home and community

Specially trained teams

- Strengths-based and trauma-responsive care
- Developmentally-attuned and customized to the needs of youth and families

Robust follow-up services

- Support stabilization and connection to resources

Program Goals

Reduce	out-of-home placements for children and youth
Reduce	emergency department use for mental health needs
Reduce	new entries into foster care and placement changes for those already in foster care
Divert	children and youth with unmet mental health needs from the juvenile justice system
Improve	school outcomes
Improve	mental health symptoms (e.g., anxiety, depression, harm to self)

Texas YCOT Teams

Bluebonnet Trails:
Bastrop County
Burnet County
Caldwell County
Fayette County
Gonzales County
Guadalupe County
Lee County
Williamson County

Border Region Behavioral Health Center:
Jim Hogg County
Starr County
Zapata County
Webb County

Burke Center:
Angelina County
Houston County
Nacogdoches County
Newton County
Polk County
Sabine County
San Augustine County
San Jacinto County
Shelby County
Trinity County
Tyler County

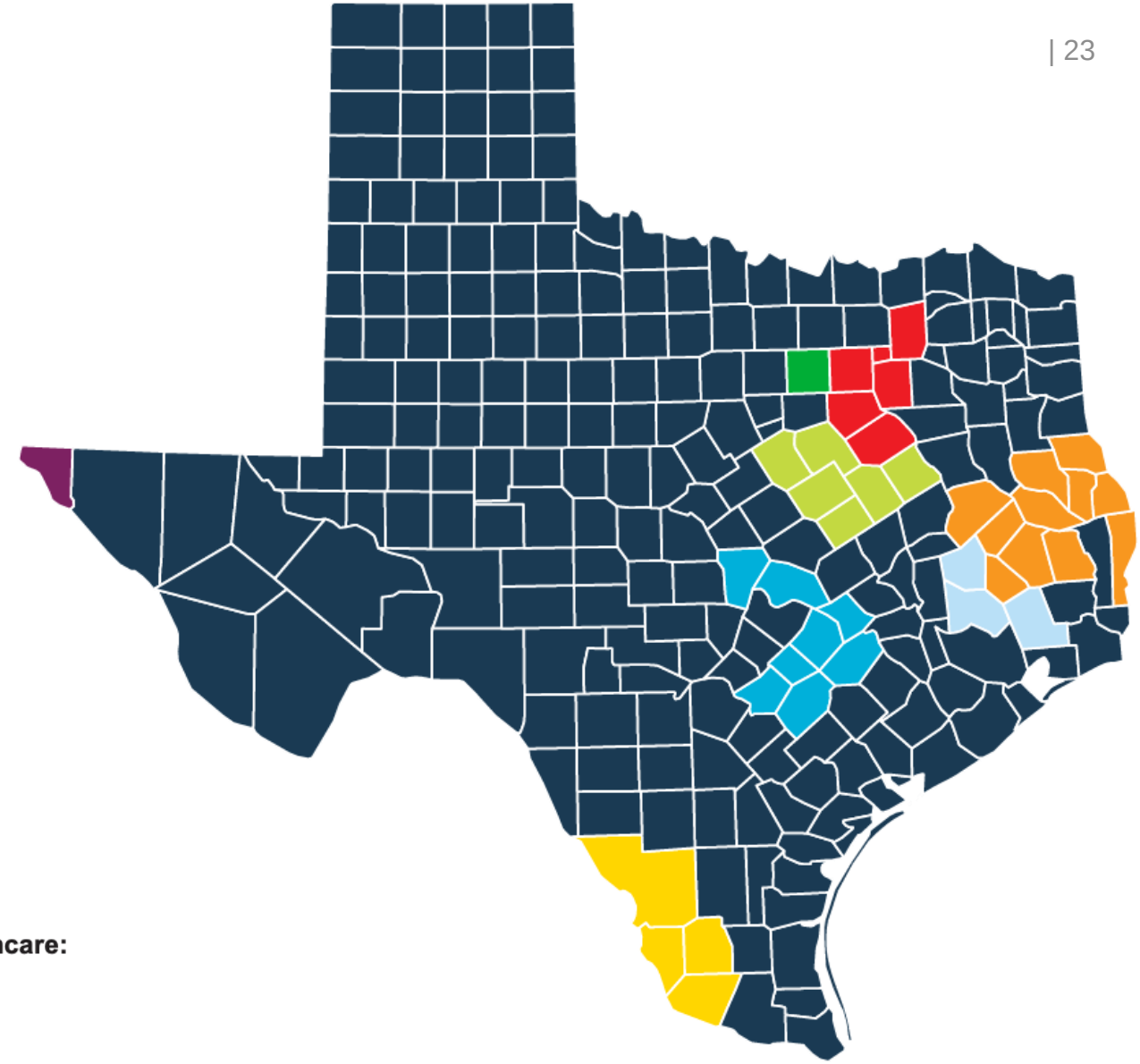
Emergence Health Network:
El Paso County

Heart of Texas:
Bosque County
Falls County
Freestone County
Hill County
Limestone County
McLennan County

My Health My Resources of Tarrant County:
Tarrant County

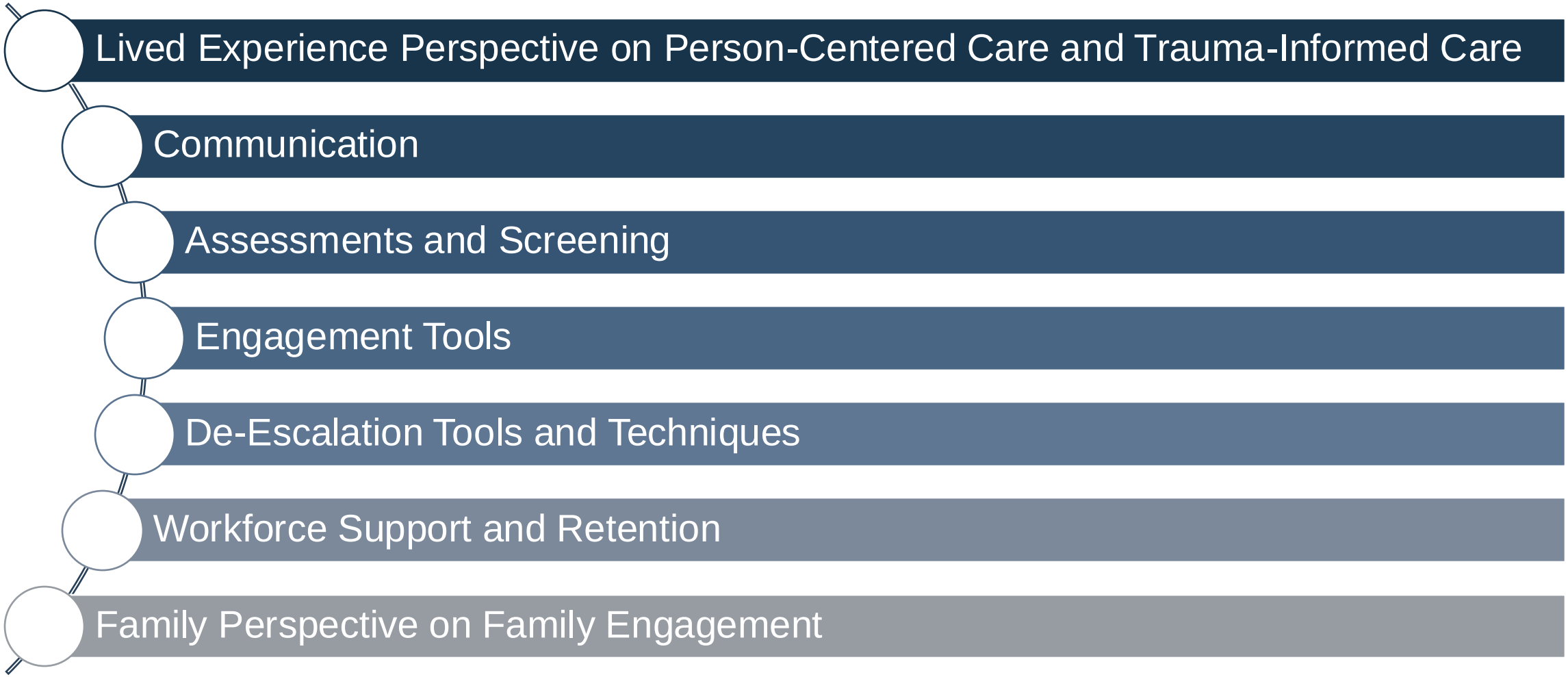
North Texas Behavioral Health Authority (NTBHA):
Dallas County
Ellis County
Hunt County
Kaufman County
Navarro County
Rockwall County

Tri-County Behavioral Healthcare:
Liberty County
Montgomery County
Walker County



Best Practices

Best Practices Overview



Welcome to

Person-Centered Planning: A very brief overview

Your Trainer is:

Jordan Smelley, MHPS,

Certified People Planning Together Trainer

My Life….My Plan…

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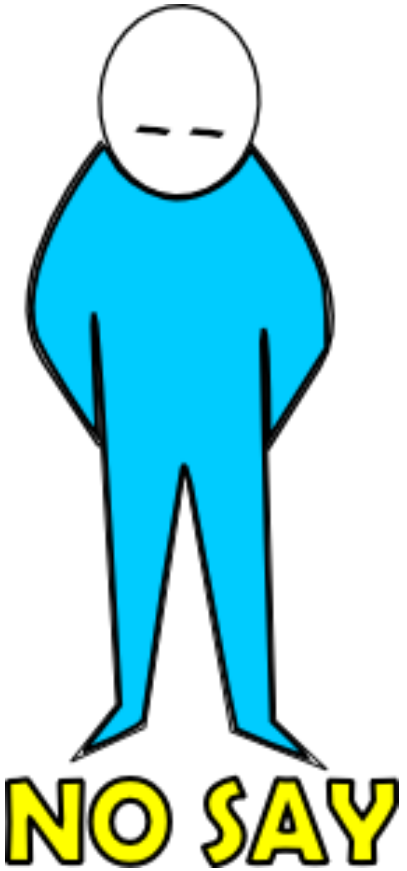
Have you . . .

Ever been to a meeting

where you didn’t say anything?

Ever felt you did not have a say over your life?



What is Person Centered Planning?

https://www.youtube.com/watch?v=2REk6fYDZ0Y

One-Page plan from People Planning Together training

Jordan 's One Page Plan

I'm a certifed Mental Health Peer Specialst and People Planning Together Trainer

My Outcome Statement

Obtain employment where I can use my skills as both a Mental Health Peer Specialist and a certified People Planning Together Trainer.

What's Important To Me

- listening to music or playing piano to help me with emotional regulation
- Hanging out with my niece and nephew.
- Hanging out with my girlfriend Sarah
- Hanging out with Scotty who is my best friend since I was in 6th grade

What's Important For Me & How to Support Me

- Respond to emails I send within 72 hours when possible
- I shut down when yelled or cussed at
- I need to be able to use my weight vest or blanket when upset or overstimulated
- have clear transition between topics you are discussing with me
- Be willing to rephrase things until I understand

ACTION STEP	BY WHEN	WHO WILL HELP?
Fill out at least 1 job application	12/31/2025	TWC-VR counselor
continue legal process to obtain medically necessary med	ongoing	legal resource like paxton ai
continue behavioral health treatment to maintain stability	ongoing	psychiatrist and therapist

Considerations for Creating a Person-Centered Plan

1. To satisfy "Important For" to be met, it must be linked to an "Important To" for the person receiving services. Here is an example: https://youtu.be/IzojVg-zV0A.
2. The person receiving services picks who is a part of their planning process.
3. A person-centered plan must contain a method that is agreed upon by all members of the planning process.
4. A person-centered plan must be written in plain language and a copy must be provided to the person receiving services at the end of the planning meeting.
5. A person-centered plan must address how the person receiving services wants and needs to be supported.
6. Person-centered plans should include opportunities for persons receiving services to explore their interests and talents as a career path, if they so choose. Here is an example of how this can look: https://www.youtube.com/watch?v=4p5286T_kn0


Be a Mr. Jensen

The Impact of Person-Centered Planning

- Person-centered planning shifts the focus of systems of support from a solely clinical aspect with little to no input from the person receiving services to giving the person receiving services a voice and empowering them to communicate how they wish to be supported.
- Person-centered planning uses a trauma-informed approach that naturally decreases the odds of traumatizing or re-traumatizing persons receiving services.
- Person-centered planning allows for the persons receiving services to develop coping mechanisms and self expression as they problem solve. Here is an example: https://youtu.be/KL5-15C4t4I.

Thank you!

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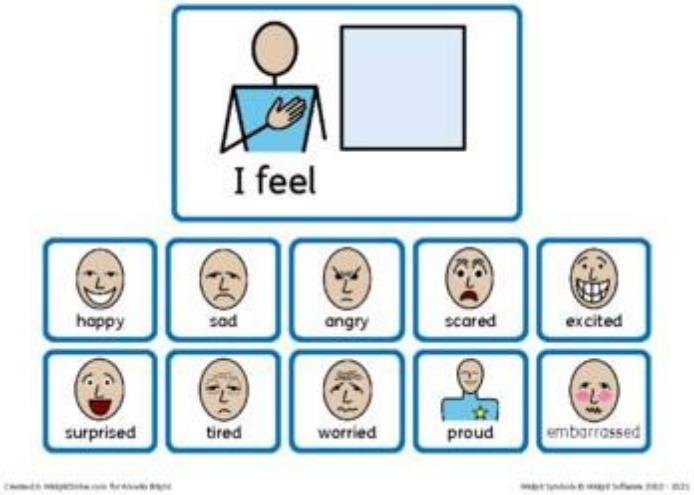
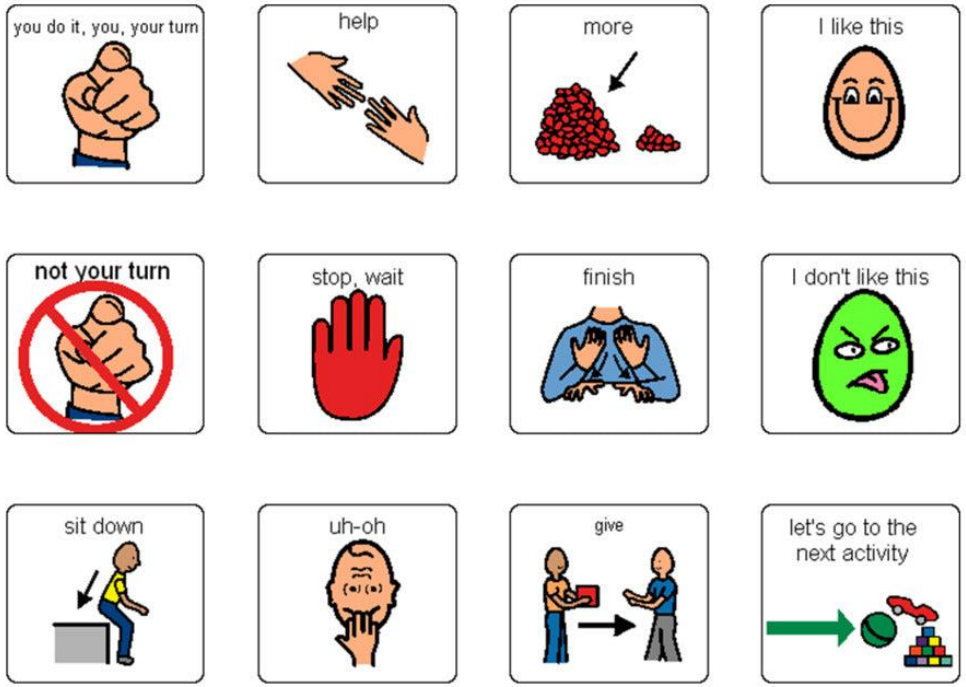
Communication

- Be mindful of body language
- Don't assume someone can or cannot communicate verbally
- Start with yes or no questions and do not require a verbal response
- Slow down – be flexible and prepare to allow extra time
- Use plain language - AI can help to make things easier to read and understand
- Identify and reduce potential distractions
- Check for understanding and ask for ongoing feedback about how you can communicate better with the individual and make requested changes
- Be prepared to have multiple ways of getting information when verbal language is a barrier
  - "Show me"
  - Use icons and visuals
    - Utilize PECS (Picture Exchange Communication System)
    - Social Stories



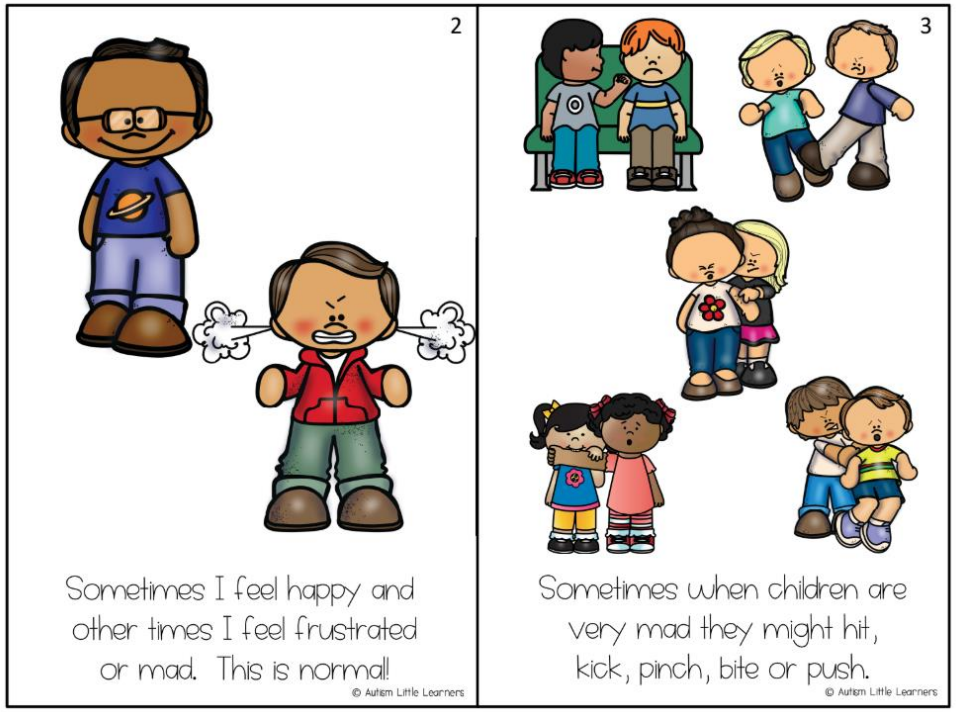
Communication:
Picture Exchange Communication System (PECS)



'Taking turns'

- Useful for verbal and non-verbal individuals
- Relieves frustration caused by not being able to communicate
- Can be personalized[9]
- Use them proactively and regularly so that it is easier to use them in times of distress

Communication: Social Stories



- Walks a person through a situation.
- Can help youth know what to expect in certain situations, minimizing anxiety and uncertainty.
- Can assist with skill building such as resilience, coping skills, social skills, etc.[10]
- Consider having a social story available about your service!
  - Helpful guide for writing a social story: https://vkc.vumc.org/assets/files/tipsheets/socialstoriestips.pdf

Assessments and Screenings: General Notes

- Challenges with assessments and screeners:
  - Many existing tools miss key differences between youth with DD and youth without DD.
  - Very few have been validated for use with youth with DD (and with those few, access is limited).
  - With assessments/screeners of youth with DD, most heavily rely on parent/caregiver report.
- During this process, consider medical contributions to dysregulation (e.g., "are you hungry?" "how much sleep did you get last night?" "when is the last time you went to the bathroom?").
- Honor and prioritize youth self-report, autonomy, and agency.

Assessments and Screenings: General Notes

TABLE 1. Methods for adapting material to I/DD learners.

Modality	Recommendation
Visual	Present information using visual cues
	Avoid visual clutter by using large, easy to read font (14-point or higher)
	Use only one side of the page
	Break up large chunks of text (use multiple pages if necessary)
Content	Use simple and concrete language (avoid abstract language and verbosity)
	Present information in an organised and structured way
	Limit the amount of information on a page
Teaching	When teaching new information, use repetition of small chunks
	Allow opportunity for learner to repeat information to clarify comprehension
	When appropriate, model and practice
Augmentative and Alternative Communication	Ensure device or communication strategy/materials are preloaded with vocabulary related to subject matter

Note: Recommendations based on accommodation suggestions from PACER Center, 2018; Martin, 2009; and Van Bourgondien & Coonrod, 2013.

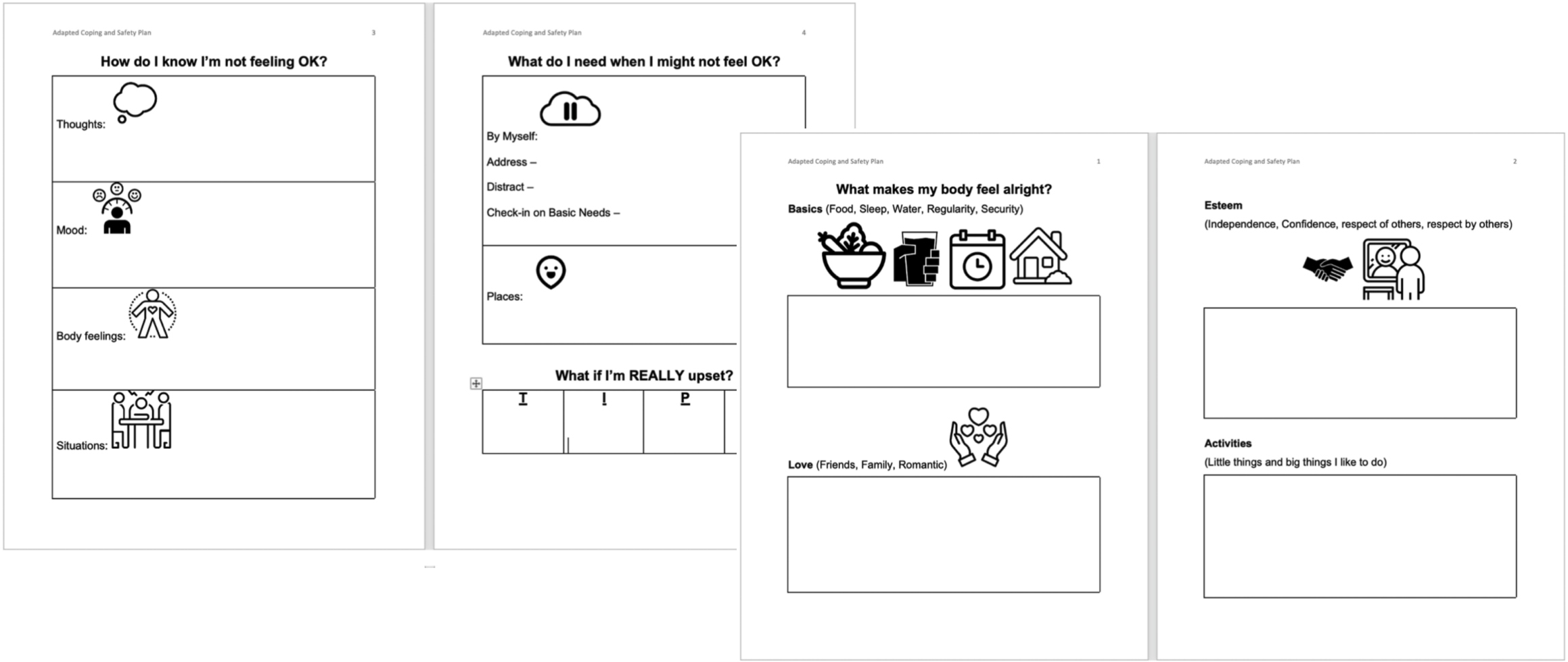
Modify existing tools to be less reliant on verbal cues and integrate other communication and learning approaches.

NOTE: Image citation is on Reference slides, number 11

Assessments and Screenings: Suicide Assessment and Planning

- There is a lack of tools to assess for suicidality in youth with Developmental Disabilities (DD).
- Suicidal ideation, suicidal behaviors, and risk factors may look different in youth with DD.[11]
  - Existing screening tools may miss key information.
- Traditional safety planning interventions usually rely on written texts and verbal prompts between clinician and youth.
- Screening procedures should include the following:[11]
  - Family bereavement;
  - Abuse;
  - Interpersonal distress; and,
  - Changes in functional skill level or outward behaviors (need to understand baseline).
- Focus on the basics of suicide risk assessment regardless of tool: plan, intent, means.

Adapted Safety Plan



NOTE: Image citation is on Reference slides, number 11

Assessments and Screenings: Suicide Assessment and Planning

Resources:

- Training for 988 National Suicide Lifeline Screeners: Suicide Screening for People with ASD-IDD/MH
- Current research and development of autism-specific suicide risk assessment tools and management strategies (learn more here).
- Understanding and Preventing Suicide in People with IDD: Experiences Learned from a Collaborative Research Project
- Safety Planning Intervention for Autistic Individuals - SPI-A (click here for presentation on using this tool)
- Texas HHSC Flyer – Suicide Prevention for Individuals with IDD

Engagement Tools

- Focus on connection and rapport before anything else
  - The best tool you have is yourself!
  - Monitor your body language, tone of voice, and the language you use to convey safety, validation, trust, etc.
  - Be aware of desire to control, diminishing agency and autonomy
- Be adaptable to the preferences of the youth (e.g., eye contact preferences)
- Sample tools:
  - Incredible 5-Point Scale (video)
  - Using Self-Awareness to Advocate for Support Needs in Different Environments (Jordan)

https://www.5pointscale.com/

Calming and De-Escalation Techniques

https://www.etsy.com/listing/1093471185/emdr-butterfly-hug-visual

Stay calm when working with a distressed youth. Remember, we co-regulate.

Grounding Exercises

- Breathing Exercises - Belly Breathing
- Push Palms or Foot Press
- More examples - https://caps.arizona.edu/grounding

Bilateral Stimulation

- "Butterfly Hug" or "Gorilla Taps"
- More examples - https://www.emdria.org/blog/emdria-members-respond-creative-bls-with-children-and-adolescents/

Be ready to explain how to do these verbally but also have printed instructions with visuals to leave behind. It takes time to develop these skills and visual cues can help people practice later.

Workforce Support and Retention

- Need for well-rounded training
  - Proactively developing healthy relationships with clients
  - Teaching clients to manage distress
  - How to manage crises
- Importance of reflective practice
  - How does the work impact me?
- Importance of teamwork
  - Others having your back
- Importance of supportive leadership
  - Ongoing supervision
  - Opportunities to debrief following stressful incidents

Family Perspective

- Effectively partnering and collaborating with parents, caregivers, and family members
- Effective and appropriate use of Family Partners in crisis response
  - Combat social isolation
  - Provide a lifeline
  - Build trust and engagement

Q & A

Next Steps

Future trainings?
We need your input!

Please take a moment to complete this survey.
https://www.surveymonkey.com/r/QWTPW87

Questions

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Additional Resources

Webinar hosted by Integral Care – Psychiatric Difficulties and their Effect on Individuals with Intellectual and/or Developmental Disabilities - https://hublearningcommunity.squarespace.com/upcoming-opportunities

Jordan Smelley, Mental Health Peer Specialist – https://www.jordansmelleyprss.com/worksheets

Dr. Karyn Harvey – https://karynharvey.org/

National START Center Trainings – https://iod.unh.edu/national-center-start-services/training-professional-development

Thank You!

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CENTER FOR CHILD
AND FAMILY WELLNESS

CENTER FOR JUSTICE
AND HEALTH

CENTER FOR HEALTH
SYSTEM TRANSFORMATION

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