NCTSN The National Child Traumatic Stress Network

Hogg Foundation for Mental Health
ADVANCING RECOVERY AND WELLNESS IN TEXAS

The Road to Recovery:
Supporting Children with IDD Who Have Experienced Trauma
Facilitator Guide

November 2015

About the National Child Traumatic Stress Network

Established by Congress in 2000, the National Child Traumatic Stress Network (NCTSN) brings a singular and comprehensive focus to childhood trauma. NCTSN's collaboration of frontline providers, researchers, and families is committed to raising the standard of care while increasing access to services. Combining knowledge of child development, expertise in the full range of child traumatic experiences, and dedication to evidence-based practices, the NCTSN changes the course of children's lives by changing the course of their care.

About the Hogg Foundation

The Hogg Foundation for Mental Health has been promoting mental health in Texas since 1940, when the children of former Texas Governor James S. Hogg established the foundation with proceeds from their beloved brother Will's estate. Will's sister, Miss Ima Hogg, later established a separate endowment at the foundation dedicated to providing mental health services for children, youth and their families in Houston and Harris County. Over the years, the Hogg Foundation has awarded millions of dollars in grants and scholarships to fulfill this mission and continue the Hogg family's legacy of public service in Texas. Today, the Hogg Foundation focuses on key strategic areas with the greatest potential to benefit mental health in Texas and awards grants through a competitive proposal process. The foundation funds mental health services, scholarships, academic research, policy work, public education and outreach.

Acknowledgments

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Contents

Preparing for the Training

The *Facilitator Guide* contains guidance and tips for presenting the content and conducting training activities. PowerPoint slides can be found on the Trauma and IDD Toolkit webpage on the NCTSN Learning Center (see the *About This Toolkit* section for more information).

Slides are numbered consecutively beginning with Slide 1 for Day 1 and Day 2. Each slide includes notes to provide the facilitator with background information for the content of the slide. Slides with activities include descriptions of the activity, references to any handouts that accompany the activity (found in the *Participant Manual*), length of time to complete the activity, and any additional materials that are required.

Each slide header may show up to five different icons on the right hand side which are designed to prompt the facilitator about specific action that needs to be taken for the content on that slide:

- **Animation**: This symbol indicates that the facilitator should click on the space bar to advance content on a particular slide.
- **Activity**: This symbol indicates that there is an activity associated with this slide. Activities include brief discussions as well as more in-depth learning tools with handouts or other materials. The slide header notes length of time for activities that are longer than a couple minutes.
- **Supplemental Materials**: This symbol indicates that there is more information about the content of this slide in the Supplemental Materials section, which the facilitator may want to familiarize him/herself with prior to conducting the training. The slide header, in the *Facilitator Guide*, will indicate which page numbers are being referenced.
- **Participant Manual**: This symbol indicates that the facilitators should alert participants to handouts in their *Participant Manual*. The slide header, in the *Facilitator Guide*, will indicate which page numbers are being referenced.
- **Video**: This symbol indicates that there is a video on the slide. The videos in the training have been designated as "optional," as they may require purchasing and/or may not fit the needs of the group. Note that the videos that are suggested have limitations in that they do not feature children with visible disabilities, are not close-captioned, and are

not very diverse. They have been included in the Toolkit, with the "optional" designation, in order to demonstrate areas where it may be good to break up didactic content with a video. The Videos section (see Appendix B) has more information about where videos can be purchased, as well as ideas for additional videos facilitators may want to include in the training. Additionally, Appendix C provides instructions on how to embed videos into PowerPoint slides.

Additionally, prior to the training, facilitators should:

- Request that the training room be set up with five or six round tables with five to six people per table.
- Review the Sample Agenda, Materials Checklist and *Facilitator Guide* to understand the philosophy and organization of learning activities.
- Familiarize themselves with the Evaluation Activities in the "What Can a Provider Do?" sections in Modules 1–6 (i.e., Day 1 Slides 30, 55, 81; Day 2 Slides 28, 60, 85) and with the Optional Follow-Up Activity (*Facilitator Guide:* Appendices D & E), which are both teaching and evaluation tools.
- Identify videos to use in the training and embed them in slides (see Appendix C).
- Review Appendix A of the Facilitator Guide, *Learning Objectives for Case Vignettes,* for ideas for discussion points to highlight during activities that use the vignettes.
- Prepare Living with IDD Post-It Activity (Day 1, Slide 52): write the following words at the top of each of 10 large Post-It papers:
    1. Self-care
    2. Communication
    3. Mobility
    4. Interpersonal Dynamics & Relationships
    5. Home Living
    6. Community Use
    7. Health
    8. Safety
    9. Leisure
    10. Education/School
- Prepare six (one per table) copies of the Board Game (Day 2, Slide 26). One copy is included in the Toolkit.
    - There are two PDF versions of the Board Game on the NCTSN Learning Center. A 17x22 version and a version that can be printed on four 8.5x11 pages and taped together.
    - Print and cut out the brick and water cards, as well as the board game markers.
    - Prepare to have two dice per Board Game.
    - Collect all the parts of the Board Game in a plastic envelope so that a copy can be placed on each table in the training at the beginning of Day 2.
- Review resources in the Supplemental Materials section (books, publications and websites) to update/increase knowledge of child traumatic stress.
- Consider reviewing *A Risk Reduction Workbook for Parents & Providers* (2nd ed) by Nora Baladerian for additional ideas on case examples to share during the training.

Materials Checklist

Trainer Note: Materials are listed in the order they appear throughout the Trainer's Guide.

- ☐ Laptop and LCD projector
- ☐ Speakers
- ☐ Remote Presentation Clicker (optional)
- ☐ Participant Manual, including Slidekit, for each participant
- ☐ 10 large pieces of Post-it® Flip chart paper & markers (Day 1, Slide 52)
- ☐ 2"-square size Post-it® notes, 2-3 packs per table (Day 1, Slide 52)
- ☐ Materials for Game Board (Day 2, Slide 26: this requires advance preparation)
- ☐ 2 Dice per table (Day 2, Slide 26)
- ☐ Tape, to piece together the Game Board (Day 2, Slide 26)
- ☐ Prizes (optional; for any/all activities)

Essential Messages

1. Know that there's hope; recovery from traumatic experiences is possible. *(Module 1)*
2. Recognize that a child with IDD may have had a traumatic experience(s), which can have profound effects. *(Module 1)*
3. Recognize a child's developmental level and how IDD and traumatic experiences are affecting his/her functioning. *(Module 2)*
4. Utilize a developmental lens when making meaning of a child's traumatic experiences and responses. *(Module 2)*
5. Recognize that in the aftermath of trauma, understanding traumatic stress responses is the first step in helping a child regain their sense of safety, value and quality of life. *(Module 3)*
6. Utilize an IDD- and trauma-informed child-centered approach to support both the child and the family. *(Module 4)*
7. Help parents/caregivers, and other professionals in the child's life, strengthen protective factors. *(Module 4)*
8. Partner with agencies and systems to ensure earlier and more sustained access to services. *(Module 5)*
9. Ensure that trauma-informed child-centered services, treatments and systems drive the recovery plan. *(Module 5)*
10. Practice ongoing self-care in order to increase effectiveness in delivering high quality support, services and treatment. *(Module 6)*

Learning Objectives

Module 1: Setting the Stage

In this module, participants will learn why a Toolkit that addresses the needs of children with IDD who have had traumatic experiences is important.

Learning Objectives

- Recognize that children with IDD are at-risk for traumatic experiences.
- Recognize that recovery from traumatic experiences is possible.
- Establish the important role of parents/caregivers and families on the road to recovery.
- Describe frameworks that will be used to illustrate key concepts throughout the training.

Module Two: Development, IDD & Trauma

Participants will learn about typical milestones that occur throughout a child's development and how IDD and traumatic experiences can disrupt those milestones.

Learning Objectives

- Define IDD and various types of disabilities.
- Discuss developmental tasks across typical development.
- Describe how IDD and traumatic experiences may disrupt typical development.
- Identify the areas in which children's functioning is affected by IDD and discuss subsequent adaptations that must be made.

Module Three: Traumatic Stress Responses in Children with IDD

Participants will learn about how traumatic experiences affect development generally, and children with IDD specifically, by learning and comprehending the 12 Core Concepts for understanding traumatic stress responses in children.

Learning Objectives

- Define child traumatic stress and PTSD.
- Describe the 12 Core Concepts for understanding traumatic stress responses in children and families.
- Identify how traumatic experiences and their responses affect children with IDD.

Learning Objectives

Module Four: Child & Family Well-Being & Resilience

Participants will learn the role of protective factors—such as a secure attachment and a healing/protective environment—in enhancing family well-being and resilience, and how to provide practical tools and support for caregivers and parents.

Learning Objectives

- Explore the impact on parents/caregivers of learning about their child's traumatic experience.
- Explain strategies for strengthening protective factors to enhance child and family well-being, resilience and recovery.
- Describe frameworks for promoting a healing and protective environment in order to create a safe and meaningful life for children.
- Identify family-informed child-centered planning techniques to help children realize their hopes and dreams.

Module Five: IDD- & Trauma-Informed Services & Treatment

Participants will learn how to augment the protective factors of children with IDD and their families through IDD-informed trauma assessment and screening, and referral to appropriate trauma-informed services and treatment.

Learning Objectives

- Explain how to enhance protective factors of children with IDD and families through appropriate trauma-informed services & treatment.
- Discuss how to utilize adapted screening, assessment and planning tools to identify IDD- and trauma-informed needs of children and families.
- Discuss strategies for adapting the core components of trauma-informed treatments for children with IDD.
- Identify strategies for partnering with agencies and cross-system collaboration.

Module Six: Provider Self-Care

In the last module, participants will learn the difference between burnout, secondary traumatic stress, and vicarious trauma and the steps to stress reduction and self-care.

Learning Objectives

- Describe the difference between secondary traumatic stress, burnout and vicarious trauma.
- Identify how burnout develops among providers.
- Discuss potential sources, warning signs, and effects of secondary traumatic stress and organizational stress.
- Implement steps to stress reduction and self-care.

Sample Agenda: Two-Day Training

Day 1

8:30 am – 9:00 am	**Registration**
9:00 am – 10:30 am	**Module 1: Setting the Stage** ***[Slides 1-30]*** ▪ **Activity** (Introductions/Icebreaker, Slide 5): 15 minutes ▪ ***Optional*** **Video** (NCTSN PSA, Slide 6): 2:20 minutes ▪ ***Optional*** **Video** (All Behavior Is Communication, Slide 21): 4:27 minutes ▪ **Discussion** (Ask Yourself, Slide 27): 5 minutes ▪ **Activity** (Making the Connection, Slide 28): 5 minutes ▪ **Action Planning** (Essential Messages 1 & 2, Slide 30): 7 minutes
10:30 am – 10:45 am	**BREAK**
10:45 am –12:15 pm	**Module 2: Development, IDD & Trauma [*Part 2 Slides 31-50*]** ▪ **Activity** (Case Vignettes: Development, Slide 50): 20 minutes
12:15 pm – 1:15 pm	**LUNCH** ***(prep Living with IDD/Post-It Activity, Slide 52)**
1:15 pm – 2:30 pm	**Module 2: Development, IDD & Trauma [*Part 2 Slides 51-55*]** ▪ **Activity** (Living with IDD, Slide 52): 15 minutes ▪ **Action Planning** (Essential Messages 3 & 4, Slide 55): 7 minutes **Module 3: Traumatic Stress Responses in Children with IDD [*Part 1 Slides 56-65*]** ▪ ***Optional*** **Video** (ReMoved, Slide 58): 6 minutes
2:30 pm – 2:45 pm	**BREAK**
2:45 pm – 4:00 pm	**Module 3: Traumatic Stress Responses in Children with IDD [*Part 2 Slides 66-82*]** ▪ ***Optional*** **Video** (Who We Are, Slide 67): 5:22 minutes ▪ **Activity** (Case Vignettes: Responses, Slide 79): 20 minutes ▪ **Action Planning** (Essential Message 5, Slide 81): 5 minutes ▪ **Post-Training Evaluation** (Day 1, Slide 82): 5 minutes
4:00 pm – 4:15 pm	**Wrap Up Day 1**

Day 2

9:00 am – 10:30 am	**Module 4: Child & Family Well-Being & Resilience** ***[Part 1 Slides 1-23]*** ▪ ***Optional* Video** (Enhance Child Well-Being, Slide 9): 6:42 minutes ▪ **Discussion** (Ask & Answer Questions, Slide 11): 5 minutes ▪ **Activity** (Local Resources, Slide 23): 15 minutes
10:30 am – 10:45 am	**BREAK** ****(prep Board Game Activity, Slide 26)***
10:45 am –12:00 pm	**Module 4: Child & Family Well-Being & Resilience** ***[Slides 24-28]*** ▪ **Activity** (Board Game, Slide 26): 30 minutes ▪ **Action Planning** (Essential Messages 6 & 7, Slide 28): 5 minutes **Module 5: IDD- & Trauma-Informed Services & Treatment** [***Part 1 Slides 29-47***]
12:00 pm – 1:00 pm	**LUNCH**
1:00 pm – 2:30pm	**Module 5: IDD- & Trauma-Informed Services & Treatment** [***Part 2 Slides 48-60***] ▪ **Activity** (Fish Bowl, Slide 48): 30 minutes ▪ ***Optional* Video** (Components of Treatment, Slide 50): 6 minutes ▪ **Activity** (Case Vignettes: Accessing Services, Slide 58): 20 minutes ▪ **Action Planning** (Essential Messages 8 & 9, Slide 60): 5 minutes
2:30 PM – 2:45 PM	**BREAK**
2:45 pm – 4:00 pm	**Module 6: Provider Self-Care [*Slides 61-88*]** ▪ ***Optional* Video** (Trauma Stewardship, Slide 63): 2:16 minutes ▪ **Activity** (Stress Warning Signs, Slide 68): 5 minutes ▪ **Activity** (Self-Care Options, Slide 70): 3 minutes ▪ **Activity** (Breathing Exercise, Slide 72): 2 minutes ▪ **Activity** (Balancing Your Self-Care, Slide 73): 5 minutes ▪ **Action Planning** (Essential Message 10 & Personal Trauma-Informed Action Plan, Slide 85): 15 minutes ▪ **Post-Training Evaluation** (Day 2, Slide 86): 5 minutes
4:00 pm – 4:15 pm	▪ Wrap Up Day 2

Facilitator Notes: Day 1
Module 1: Setting the Stage

SLIDE 1

***The Road to Recovery: Supporting Children with IDD Who Have Experienced Trauma* training**

Hello Everyone. Welcome to *The Road to Recovery: Supporting Children with IDD Who Have Experienced Trauma* training.

SLIDE 2

Module 1: Setting the Stage

- This training is broken up into 6 modules. In these modules, you'll learn about best practices and techniques to help reduce the stress faced by children with IDD who have also experienced trauma. By understanding development, traumatic stress, and the nuances of working with children with IDD you'll become more effective at your job, and find more reward in working with the children and families in your care.
  - **Module 1: Setting the Stage**—In this module, you will learn why a Toolkit that addresses the needs of children with IDD who have had traumatic experiences is important.
  - **Module 2: Development, IDD & Trauma**—You'll learn about typical milestones that occur throughout a child's development and how IDD can detour those milestones.
  - **Module 3: Traumatic Stress Responses in Children with IDD**—You'll learn about how traumatic experiences affect development generally, and children with IDD specifically, by learning about the 12 Core Concepts for understanding traumatic stress responses in children.
  - **Module 4: Child & Family Well-Being & Resilience**—You'll learn the role of protective factors—such as a secure attachment and a healing/protective environment—in enhancing child & family well-being & resilience, and how to provide practical tools and support for caregivers and parents.
  - **Module 5: IDD- & Trauma-Informed Services & Treatment**—You will learn how to augment the protective factors of children with IDD and their families through IDD-informed trauma assessment & screening, and referral to appropriate trauma-informed services & treatment.
  - **Module 6: Provider Self-Care**—In the last module, you'll learn the difference between burnout, secondary traumatic stress, and vicarious trauma and the steps to stress reduction and self-care.
- A couple of notes about this training:
  - The training is conceptualized as an introductory training and designed to be used with a more advanced training in the future (e.g., treatment adaptations for children with IDD).

- The training tries to balance breadth vs depth of information, erring on the side of breadth. The goal is not to go over every different type of IDD or trauma, but to provide general information and questions that can be applied to a variety of types.

SLIDE 3
Self Care Alert!

- The topics we are going to cover may be upsetting to some of you. They may bring up difficult memories of clients that you've helped. Your heart goes out to these kids and families. They are vulnerable. It's bad enough when a child without disabilities has a traumatic experience, but we have even more intense and strong responses when a child with disabilities has a traumatic experience. It evokes feelings of unfairness and injustice, and enhances our desire to protect. We feel that society should pay even more attention to vulnerable people and those we believe need to be protected.
- You may have friends, or yourself have a child with IDD. The material in this training may bring up feelings and thoughts related to your experiences.
  - Please feel free to step out of the room at any time during the presentation.
  - Alternatively, it is okay to stay in the room, even if you are feeling emotional.
  - We strongly encourage you to take care of yourself not only during this training but also in your work setting. We will talk more about the importance of self-care in Module Six.

SLIDE 4
Module 1: Learning Objectives
What Will I Learn Today?

After completing today's training, you should be able to do the following:

1. Recognize that children with IDD are at-risk for traumatic experiences.
2. Articulate that recovery from traumatic experiences is possible.
3. Establish the important role of parents/caregivers and families on the road to recovery.
4. Describe frameworks that will be used to illustrate key concepts throughout the training.

SLIDE 5
Interacting Influences

15 MIN

TRAINER TIP: *Who's in the room? What are the frameworks you use in your work? Use this first question as an ice breaker. This is a good point to briefly define IDD and trauma—note that they will be further defined through the course of the training but participants may feel lost if they have to wait for the full definitions.*

TRAINER TIP: ***Optional Exercise.*** *Ask participants to stand up, move around the room and find out from one another, how many years of experience they each have working with children with IDD who have had traumatic experiences. Ask participants to form a circle in order of their number of years of experience. Help participants identify where the beginning of the circle (fewer years of experience) and end of the circle (more years of experience) are. Once participants have formed the circle, go around the circle and have each person introduce themselves and their experience doing this work. This is a good technique to get participants moving around early in the training, and also to start to get to know one another. Additionally, it honors the wisdom and experience in the room when a training audience includes veteran participants. The facilitator can share a rough estimate of the number of years of experience in the room and make the point that we can all learn from one another over the course of the training, and then mention looking forward to hearing ideas and wisdom from participants, as well as fresh ideas from newer participants.*

- Mental health and trauma treatment providers may have a variety frameworks or theoretical orientations that guide their work (e.g., CBT, family systems theory, psychoanalytic theory), however generally the focus is on recovery and resilience—the perspective that people can recover or enhance their functioning.
- Providers in the IDD world tend to use frameworks that focus on creating adaptive environments to increase opportunities and build skills. Recovery isn't necessarily a familiar term in the IDD world. We want to change that, incorporate it into our daily language.
- This Toolkit seeks to do both: focus on creating adaptive environments to increase opportunities (e.g., support health and safety) and recovery (build children back up, help them overcome traumatic experiences and feel good about themselves again).
- How are these frameworks similar or different? What roles do participants have? *[Allow 7 minutes for participants to discuss this question at their tables. Once the time has elapsed, have each participant introduce themselves and say something BRIEF about the framework he/she uses.]*
- A note about definitions:
  - **IDD**: the Toolkit is focusing on intellectual and developmental disabilities, broadly. We recognized that within IDD there is a wide range of functioning and individuals vary in terms of the challenges they experience, depending on the nature of their disability. While generalizations are not

possible, the purpose of the Toolkit is to identify some specific issues and examples that allow providers to think about the types of questions that may be important to further explore when working with children with IDD. We will further define IDD in Module 2.

- The Toolkit frequently refers to using "trauma-informed" supports and services, which refers to a recognition and response to traumatic experiences. For example a trauma-informed approach would consider the question, "what happened to you?" as opposed to "what's wrong with you?" Traumatic stress, supports and services will be specifically defined in Module 3.

SLIDE 6 (OPTIONAL)
Changing the Course of Children's Lives by Changing the Course of Their Care

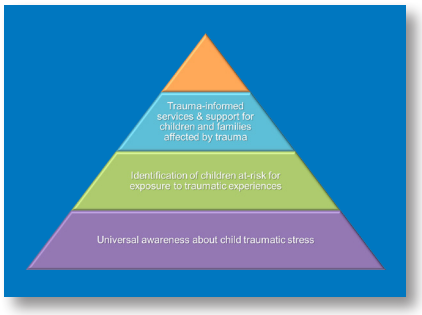
2:20 MIN

TRAINER TIP: *This 2:20 NCTSN PSA may be a good video to show, particularly if the audience of participants are non-NCTSN members.*

- This NCTSN video describes the prevalence of child trauma and the importance of changing the course of children's lives by changing the course of their care.
- Source: National Child Traumatic Stress Network, www.NCTSN.org.

SLIDE 7
The Goal

- The mission of the National Child Traumatic Stress Network is to **increase awareness** about the impact of child traumatic stress.
- One of the ways we do this is to identify specific populations of children who are **at-risk** for exposure to traumatic experiences, such as children with IDD. This will be discussed in greater detail in Modules 2 and 3.
- Therefore it is essential that as a protective and preventive step, providers learn how children are affected by child traumatic stress, which will be discussed in Modules 3 and 4.



- When a traumatic experience occurs, children should be provided **trauma-informed support and services**, including appropriate trauma screening and assessment, which may then identify children who are in need of **trauma-informed treatment**. This will be discussed in Module 5.

SLIDE 8
The Diagnostic Complexity of Trauma and IDD

Providers need to disentangle responses related to:

- Situational stressors and known developmental challenges
- Medical issues
- Co-occurring conditions
- Traumatic experiences
- Communication challenges
  - Many providers don't know what to do if a person is non-verbal or has difficulty expressing what has happened or how they feel. Kids with IDD may have difficulty understanding and expressing or putting into words their emotions or fears.
  - This leads to difficulty in diagnosing and treating a child with communication deficits.
- Parents of children with IDD often have great difficulty accessing effective supports and services.
  - Right up front we need to start thinking about using a care coordination or case management approach versus a traditional therapeutic model. The goal is recovery, not just identifying adaptive opportunities or changing behavior.

Children with IDD may struggle to express their emotions verbally.

  - How do agencies and avenues of care adjust to additional requirements of a child with IDD? Now add on top of that one who has also had a traumatic experience?
  - Parents of children with IDD often report unrelenting stress when they cannot obtain the help their children need.

SLIDE 9
"We went to them and they had <u>no idea</u> how to help us."

- Anyone ever had a client say this to them? *[If someone raises their hand or is shaking their head ask them how they responded.]*
- Children with IDD are at elevated risk for challenging behavior. The needed expertise to help them is not easily found in many communities, and even less so when trauma is involved.

SLIDE 10
Myths about Children with IDD

- It's important to be aware of your biases and perceptions when it comes to youth with IDD.
- Read a few of the following bullet points:
  - Children with IDD cannot engage in treatment.
  - Standard mental health treatment is ineffective for children with IDD.
    - ✓ We also know that this is not accurate given that there is an increasing amount of research and anecdotal case examples supporting the effectiveness of adapted trauma treatment for this population.
  - Behavior modification is the only option.
  - Youth with intellectual disabilities do not experience trauma.
    - ✓ We know that this is not true. In fact, we understand that the opposite is true given what we know about the relationship between personal resources and traumatic stress resiliency.
  - Working with this population requires significant specialized training.
    - ✓ The truth is that while it is important to obtain training on IDD and trauma, it does not require *significant* specialized training for qualified trauma therapists to provide treatment to children with IDD.
  - A challenging behavior is explained by an intellectual disability.
    - ✓ Challenging behavior may result from many things, including pain from a medical illness, a psychiatric disorder such as depression or anxiety, distress that is hard to communicate, and trauma.

  - Children with IDD are protected from trauma because of their mental age (i.e., babies); they do not remember.
  - Recognize that IQ scores don't tell you anything about the adaptive functioning of the child, about any traumatic experiences & responses or the emotional state of a child.
- This obviously isn't the entire list. Is there anything that you think we left out that should be mentioned today? *[Allow participants to shout out answers if they want to add something.]*
- These statements are not true, but are commonly believed and contribute to children with IDD who have experienced trauma not receiving the care and treatment that they need. Through the course of this training, we will disprove these myths.

SLIDE 11
Partnering with Families

TRAINER TIP: *Read the quote.*

- Respect parent & caregiver information, as well as the youth with IDD.
- Keep the family's and youth's goals and desires front and center in your work.
- It is important to realize that parents of children with IDD may have felt disrespected in the past by providers who blamed them for their child's behavior.
- When we refer to parents/caregivers in this Toolkit, we are referring to the most primary/permanent person in the child's life.

SLIDES 12-13
Trauma & IDD: Scope of the Problem

PP 3-4

- Children with IDD are at-risk for having traumatic experiences.
- High rates of out-of-home placements
  - Result in inability to provide accurate information at the time of the assessment.
  - There are few peer-to-peer support networks which could provide additional sources of support for families.
  - Thousands of children across the nation are subjected to such trauma; many are subsequently placed into out-of-home foster care, institutions or the juvenile justice system. For those with underlying IDD, the ability to assimilate the issues and organize a reasonable self-supportive response may be limited—adding additional insult to primary injury.
  - Children may experience multiple disrupted placements, which may be very traumatic.
- Providers often feel insufficiently equipped to support youth with IDD and trauma histories.
  - Too often these children are seen as difficult to work with and are misunderstood, leaving clinicians uncertain about how to move forward in treatment.
  - Because of this, providers feel inadequate when working with children who have an IDD diagnosis, and more often than not, decline to work with them, leaving this population under-identified and under-served. They may also approach services in a way that is not helpful to the child, such as focusing narrowly on behaviors and compliance or overlooking the possibility that behavioral reactions are unrelated to the disability.

- Clinicians may fear, lack interest or may have resistance to acquiring cultural competency with this population due to disability stigma and lack of awareness of the problem.
- We have a lack of trained providers; they fear what they don't know and they focus on what's wrong with you vs what happened to you.

- Treatments for children with IDD often focus on behavioral compliance.
  - Traditional evidence-based trauma interventions often exclude this population.
  - The default is to utilize a behavioral focus due to communication limitations.
  - Children with IDD exhibiting challenging behaviors often do not receive state-of-the-art mental health treatment; instead the focus is often on managing their behavior with compliance as the primary goal.
  - Cultures of care in both residential and community or family settings have historically been similar with a goal of reducing maladaptive behaviors by focusing solely on consequences and replacing undesirable behavior with behaviors deemed "appropriate."
  - It may be much more helpful to address setting conditions (such as an unstable home environment or traumatic history) or antecedents to the behavior (like trauma reminders of the person or earlier frightening experiences).
  - While positive behavior management can be effective in changing challenging behaviors, if underlying trauma and other mental health issues are not addressed the likelihood of positive outcomes is greatly reduced.

Treatments for children with IDD often focus on behavioral compliance.

- Co-occurring conditions contribute to diagnostic complexity.
  - Children with IDD who require high levels of provider services may present with *co-occurring behavioral health diagnoses* including trauma and/or anxiety that can contribute to behavioral problems.
- Traumatic stress can lead to potentially chronic changes in learning (linguistic, cognitive, and social-emotional skills), behavior (adaptive versus maladaptive), and physiology (chronically activated stress response), which may place children with IDD at even further risk of becoming a *victim to further trauma*—physical, emotional, cognitive, or some combination.
- The **Supplemental Materials** section contains an annotated bibliography of Briefs written by the NCTSN Trauma & IDD Expert Panel, which provide more information on the scope of the problem.
- Children with IDD are **under-identified & under-served**, and lack trauma-informed services when required.
  - **"Diagnostic overshadowing"** is the term used when behaviors or distress are misattributed to an individual's disabilities, preventing professionals and other caregivers from looking beyond the disability and assessing for possible mental or physical illness.
    - ✓ Caregivers and family members who are accustomed to seeing their child through the lens of the disability can misinterpret behaviors that are in fact symptomatic of mental illness, distress, or past trauma.
    - ✓ In attributing challenging behaviors solely to the disability, opportunities for recovery are missed.

- ✓ This in turn results in significant problems with trauma treatment access, frequent misdiagnoses, and poor treatment quality.
- ✓ This is particularly tragic given the staggering, well-documented rates of abuse and neglect in the IDD population.
- ✓ We also know that people with IDD are less likely to spontaneously recover from traumatic stress, so the need for properly adapted trauma treatment is evident.

- Inadequate trauma screening & assessment tools. While many trauma screening and assessment tools exist, they may need to be adapted in order to be effectively utilized with children with IDD. This will be addressed more in Module 5.
- Assumptions made about (in)ability to engage in treatment.
  - ✓ Professionals often make incorrect assumptions about children with IDD and their capacity to engage in commonly-used therapeutic techniques and strategies.
- Educated providers and family members are often not exposed to cross-training for co-occurring conditions. Higher education and continuing education programs have not provided enough opportunities for building capacity to serve children with IDD who have experienced trauma and/or other mental health conditions.

- High quality integrated care is necessary and the intensive case management needed for successful trauma treatment is **resource intensive** for this population.
  - Among the professionals that do serve the IDD population, there are **high turnover rates** due to providers' secondary traumatic stress & burnout. Also, high levels of supervision and intensive case management are usually required.
  - **Authorization denials** require advocacy and complicated appeals. This takes considerable time, all of which is non-billable.
  - Programming for adults and children with IDD often includes intricate behavioral support plans, risk reduction plans, and habilitation plans, each of which requires attention to behavior, mandatory skills to teach, and documentation.
  - Diagnosis, treatment planning and crisis prevention requires a comprehensive interdisciplinary evaluation and significant expertise that may not be available in all communities. Many communities are accessing this expertise through training, online consultation and learning communities.
- **Fragmented services**
  - Availability & quality of services varies across regions, states & communities depending on funding and the structure of services.
  - Services often occur in silos.
  - Parents may have a different care coordinator and different treatment plan in each of several systems, without any of the providers talking with each other.
  - Children may be excluded from services (like mental health or trauma treatment) explicitly because of an intellectual disability.
- **Low reimbursement rates**
  - As a result of *low reimbursement rates for service*s, providers who run group homes, day habilitation programs, and the like often employ college students and those with limited education, training, or skills in providing services and care for people with IDD.

SLIDES 14-15
At-Risk for Trauma

TRAINER TIP: Be sensitive to "blaming" caregivers when indicating that there is a higher likelihood that children with IDD will be physically & sexually abused.

- Estimates vary regarding the prevalence of traumatic exposure in children with disabilities, and depend on the types of study, methodological rigor, and definition of disability (Leeb et al., 2012). Data from the annual report on child maltreatment in the United States found that **16% of unique victims of maltreatment had developmental disabilities** (DD) (US Department of Health and Human Services, 2011).
- Children with intellectual disabilities were at two times higher the risk of physical and sexual abuse than children without disabilities (Crosse et al. in 1993). Individuals with intellectual disabilities were 4 times more likely to be victims of crime than those without disabilities Sobsey et al.,1995).

- Children with DD were over twice as likely to experience *emotional neglect* (4.7/1000) compared to children without disabilities (2.3/1000).
- There is evidence that certain behaviors are a mediating factor for maltreatment in this population. Externalizing behavior, which has a greater incidence among children with DD, appears to be related to an increased risk of *physical abuse* (Gerstein, et al., 2011). Internalizing behavior or communication and learning problems are associated with increased risk of *sexual abuse* (Turner, et al., 2011).
- When children with intellectual disabilities reach adolescence, their sexual development may not be well-understood given persistent myths that this population is "asexual," or, alternatively, "hypersexual." Increased vulnerability to sexual abuse in this group stems from increased risk of early puberty, multiple caregivers providing intimate care, and educational and communication barriers.
- Domestic violence is estimated to be almost three times more likely in families of children with DD (Sullivan, 2006).
- Children with IDD are 4x more likely to be victims of crime. A study conducted using data from the National Survey of Children's Health (NSCH) found that children with special health care needs were *bullied* 1.5 to 2 times more than non-impaired children (Van Cleave & Davis, 2006).
- Also, children with IDD are often subjected to traumatizing incidents of **physical restraint and seclusion**, something their typical peers rarely encounter (Sullivan, 2006).
- Children with IDD had significantly **higher rates of emotional neglect & serious injury** compared to non-disabled peers (Sedlak, et al., 2010).
- **Psychological distress secondary to medical procedures** is another category of potentially traumatizing experience that is more common to children with IDD than to their typically developing peers. They may have chronic medical problems that necessitate surgeries and other invasive procedures.

Additional Prevalence Statistics

- *Serious harm* was estimated to occur at 8.8 per 1000 for children with a confirmed diagnosis of IDD compared to 5.8 per 1,000 rate for their non-disabled peers.
- Children with learning disabilities are less likely to be maltreated and more likely to experience *property crime* than their same-age counterparts (Sullivan, 2009, Turner et al., 2011).
- While any disability contributes to the risk of abuse, those with intellectual disabilities, communication disorders, behavioral disorders, and multiple disabilities have the highest risk of abuse and neglect (Sullivan & Knutsen, 2000).
- Children with IDD had significantly higher rates of *emotional neglect and serious injury* compared to their non-disabled peers (Sedlak et al., 2010).
- Children with IDD have a higher rate of abuse than children without disabilities (Ryan, 1994); one study found the likelihood was 1.68 times higher (Child Welfare Information Gateway, 2012).
- When children with IDD are situated in a primary household that lacks structure and, may even be, characterized by seeming chaos and threats, their ability to "track" along "typical" developmental and emotional strands can be compromised.
  - An additional challenge is that children with IDD may start off below average or "off" charts that track developmental milestones. This makes it even more challenging to assess how a traumatic experience may be affecting their functioning (using the chart), compared to typically developing peers.

SLIDE 16
Type & Timing Matters

- A core belief of this Toolkit is that children with IDD can recover from traumatic experiences.
- It is important to recognize that traumatic experiences may occur at different time points. For some children, the traumatic experience may occur after the IDD has been diagnosed, at some later point in the child's life (e.g., a deaf child who is sexually abused as a teen). For others, a traumatic experience may be the cause of the disability or result from treatment related to the disability (e.g., traumatic brain injury from a car accident).
- The type of trauma and the timing of the traumatic experience matters.
- Life experiences prior to trauma also affects how the trauma is experienced, as well as post-trauma recovery.

- In this training, we will discuss how these, and other factors, play a role in the process of recovery.

SLIDE 17
If a Trauma Occurs: Concerns & Challenges

- When trauma occurs there is a far-reaching challenge to effectively address the psychological impact of the event, seek the most appropriate balance of safety and protection, and address aspirations for a valued life.
- A common thread across much of the range of IDD is the continued dependence children with IDD have on their parents/caregivers. Therefore, critical adaptations are needed in the models of trauma-informed care and intervention strategies to incorporate best practices while ensuring the highest quality of care.
- Parents may struggle with providing a protective shield (i.e., being able to protect their child) vs. allowing managed risks.
    - There's a balance between being over-protective to reduce injury and preserve safety and allowing/providing autonomy to develop adaptive skills.
- Trauma symptoms can exacerbate family life & adjustment (e.g., couples' relationships, sibling adjustment).

Parents may worry about how the traumatic experience might impact their child's ability to attain a meaningful life.

SLIDE 18
Parents Worry that Trauma Will Affect Children's Quality of Life

TRAINER TIP: *Have a participant read the quote.*

"We worked hard to get our child the services that we could. When Sarah lost her best friend in the car accident, we felt things were put in jeopardy. We were worried about how quickly she could lose the gains she has so painstakingly made over the last couple of years, which would then affect her chance at a happy life. We felt an urgency to respond."

SLIDE 19
Parents' Desire for Safety & Protection

- Safety and protection are concerns for all parents. They live with these concerns and these concerns shift over time at each developmental stage of a child's life. Parents are always adjusting these appraisals as children become more mature and independent. Parents of children with IDD live with these added concerns and this ever-present process of adjustment to concerns may be more challenging.

- "Concerns and hopes" are not only heightened in parents of children with IDD, the are multiplied exponentially.

SLIDE 20
Recognize Parents' Hopes & Concerns

- It's important to keep in mind that safety & protection are chronic worries among parents in regard to their children. So is the promise of the fullest, most valued life their children can achieve. Both of these concerns and hopes are heightened in the parents of a child with IDD.
- Parents of children with IDD want:
  - To find & provide the best care for their child
  - To sustain & maximize their child's maturity and independence across development & changing circumstances
  - To help their child function at his/her best and attain a meaningful life

SLIDE 21 (OPTIONAL)
All Behavior is Communication

4:27 MIN

TRAINER TIP: ***Optional Video.*** *A number of videos will be suggested for use throughout the training. You'll see that it was difficult to find videos of children with IDD who have experienced trauma from diverse cultural backgrounds. While the videos are not be a representative sample, they can be used as a starting point for a broader discussion. This video, from the Ralli Campaign, may be a good video to show to illustrate the point, "all behavior is communication."*

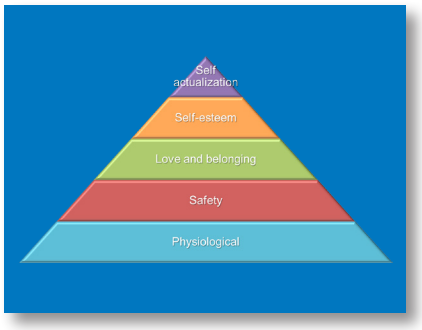
- Jake's parents describe how his behavior deteriorated when he started 1st grade. Jake tells us why he used to crawl under the table in the classroom. We learn how things changed for him once he gained the right support for his language difficulties.
- Source: Ralli Campaign, https://www.youtube.com/watch?v=WTySmn_-X80

SLIDE 22
Recovery is Possible

- When working with families, provide hope that children with IDD do recover from traumatic experiences. Listed on the slide are a few things that you can do as a provider.
- Most importantly, provide HOPE that children with IDD can recover from trauma.

SLIDE 23
What do we mean by "recovery"?

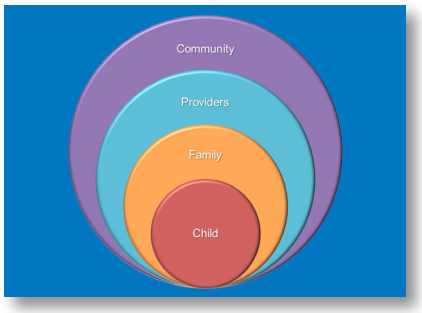
- Maslow's hierarchy of needs is an especially useful framework to consider when thinking about parents/caregivers' expectations, hopes, and dreams for their children's development.
- Parents generally wish to address all of these needs for their children. Parents of children with IDD are no different.



SLIDE 24
The Ecological Model

P 5

- In addition to Maslow's hierarchy of needs, we'll be using a number of different frameworks to highlight concepts and discussion related to IDD and trauma in this toolkit. The first is the ecological systems theory of child development, which was conceptualized by Urie Bronfenbrenner. His framework succeeded in emphasizing that there are many societal and environmental factors that influence child development.
- For the purposes of this training, the ecological model is helpful in thinking about three primary systems that we will be focusing on in this training: the child, family (defined broadly) and provider.



- See the **Supplemental Materials** section for more information about Bronfenbrenner's ecological model.

SLIDE 25
Development Across the Lifespan

PP 6-7

- Another framework we'll be using is an adapted version of Erik Erikson's theory of psychosocial development. Erikson's theory describes the impact of social experience across the lifespan and the core developmental challenge for each age range. He describes this in terms of key "conflicts" that a person experiences at each stage of development. For the purposes of this training, we've simplified Erikson's stages into the primary task for each developmental stage. There will be more on the impact of IDD and trauma on development in Modules 2 and 3.

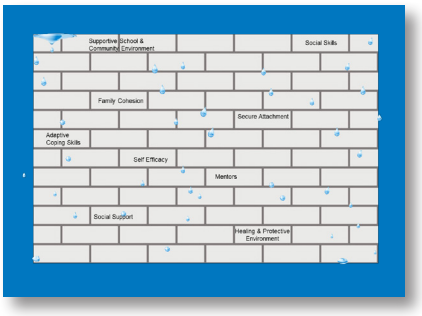
Stage	Task
Infancy	Being
Early Childhood	Doing
Middle Childhood	Mastery
Adolescence	Identity
Adulthood	Separation

- Note that this framework might not apply to families whose socio-cultural context is different than the mainstream context in the United States. One could argue that Erikson's developmental challenges are based on a Eurocentric paradigm. Developmental abilities and expectations are influenced by cultural values, and the socio-political and economic context. It is important to explore the cultural values of the child and family.
- For example, traditionally collectivistic cultures may not value (individual) identity development and separation from family as much as more individualistic cultures.
- See the **Supplemental Materials** section for more information on Erikson's theory of psychosocial development.

SLIDE 26
The Risk & Protective Factors Model

P 8

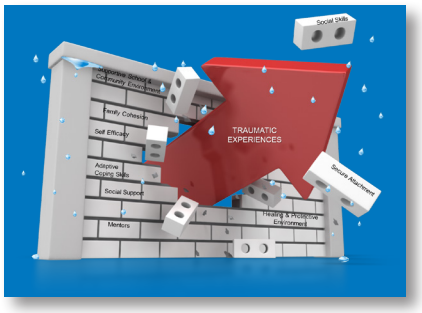
- A fourth framework that will serve as a foundation in our discussion is the risk/protective factors model. Risk and protective factors impact the trajectory of healthy development by creating disruptions and shifts over the lifespan.
- Risk & protective factors are not limited to individual behavior or access to health, but can include family, neighborhood, community, and social policy.
  - Protective factors improve health and contribute to healthy development. Think of them as bricks in a wall. There are bricks that are a natural part of the wall or that we can help children and families add to their wall that will strengthen it. Bricks like:



    - ✓ Attachment with a primary caregiver
    - ✓ Self-esteem/self-efficacy
    - ✓ Adaptive coping skills
    - ✓ Strong social support network
    - ✓ Mentors
    - ✓ Supportive school & community environment
  - Rain and water erodes the mortar and weakens the brick wall. These are risk factors. These diminish health and make it more difficult to reach one's full potential. The mortar is what strengthens the protective factors. For children with IDD, their circumstances too frequently increase their exposure to adverse events. Their disabilities affect their ability to self-soothe or participate actively in healing interventions. People with developmental disabilities are predisposed to emotional problems due to impaired resiliency (Burrows & Kochurka, 1995). They have fewer protective factors that would mitigate the effects of maltreatment (Mansell, et al., 1998), such as increased intelligence, self-efficacy, and social supports. Unfortunately many with developmental disabilities have cognitive deficits, have impaired problem solving ability, are often without adequate social supports, and have limited resources.

Rain and water erodes the mortar and weakens the brick wall.

- ✓ Emotional problems
- ✓ Behavioral/genetic/medical co-morbidities
- ✓ Cognitive deficits
- ✓ Communication challenges
- ✓ Impaired problem-solving
- ✓ Lack of social supports
- ✓ Traumatic experiences
- ✓ Higher levels of poverty & social isolation related to societal attitudes about disability



- Extending our metaphor, traumatic experiences may further weaken, or break down, protective factors.
- See the **Supplemental Materials** section for more information on risk and protective factors.

SLIDE 27
Ask Yourself

5 MIN

TRAINER TIP: *Read the slide.*

- Quickly, just off the top of your heads, what are you thinking?
- The child may act like a 7 year-old in some respects but a 15 year-old in others. It is evident that he has developmental delays/disabilities that will need to be accommodated.
- You will have to recalibrate your therapeutic approach by considering developmental tasks for both 7 and 15 year olds. Turn to your tables and discuss for a few moments how you would go about making an adjustment for this client? Is there other information you want or need? Who else do you want to speak with? *[Allow 5-6 minutes for discussion at the tables. Once time is up ask one member at each table to report out what else they'd like to learn.].*

SLIDE 28
You Can Do This Work

P 11 5 MIN

TRAINER TIP: *This is an Activity slide to help participants think about why they are doing this work. Participants will complete the,* ***Making the Connection: Why am I doing this work?*** *handout to help them identify a reason that they are in this training today. Why is this work important to them? They will be asked to think about a child with IDD who has experienced trauma and to keep that child in mind over the course of the next two days. Participants should think about that child and consider how the information they learn in the training could help them help that child.*

- There's a misconception among providers that working with children with IDD who have had a traumatic experience is completely different from working with their their non-disabled peers. This simply isn't true.
- Working with children with IDD is much more like working with typically developing youth than it's different.
  - Treatments have been adapted for children with IDD and these adaptations are more similar than different.
- Pull out your handout titled, ***Making the Connection: Why am I doing this work?*** This handout asks you to think about a child with IDD who has experienced trauma—think about a child who connects you to this work. Perhaps this is a child in your classroom or clinic, or your niece or friend. Perhaps this child is the reason you started doing this work. Perhaps this child is the reason you want to know more about IDD and trauma. As we go through the content of the Toolkit, keep this child in your mind and think about how the information you are learning could apply to this child. If you can't identify a child to think about, you can choose one of the case vignettes in your **Participant Manual** to focus on. Allow participants 5 minutes to complete the handout.

SLIDE 29
Essential Messages of Working with Children with IDD who have Experienced Trauma

- Throughout the training, we will be highlighting Essential Messages at the end of each Module. These messages pertain to the key concepts we've gone over. Here are the Essential Messages that we just covered in Module 1.

1. Know that there's hope; recovery from traumatic experiences is possible.
2. Recognize that a child with IDD may have had a traumatic experience(s), which can have profound effects.

SLIDE 30
What Can a Provider Do?

P 12 7 MIN

TRAINER TIP: *This is an Activity slide, which will recur at the end of each Module. This is the opportunity for participants to reflect on their own practice and think concretely about what they can enhance or do differently, based on the information that was just presented to them in Module 1. Participants will be given a checklist to fill out to help guide their reflections. Emphasize to participants that if they feel that the options are too clinically focused they should create strategies that are relevant to their role.*

- At the end of each Module, we will end with this question, "What Can a Provider Do?" in order to give you some time to identify i specific strategies that you would like to integrate into your practice immediately.

- Here are some things that you as a provider can do to address the concepts that we just discussed in Module 1. Think about the child you just identified who connects you to this work. What can help that child and other children with IDD who have experienced trauma? Let's take a few minutes to think about what you can do specifically in your role and at your organization to address any one of these points.
- Pull out your handout titled, ***Action Planning: Essential Messages 1 & 2***. This is your opportunity to think about how you are going to implement the ideas that we just discussed in Module 1, into your daily practice, as soon as you get back to your office. You will see that the handout outlines specific strategies for things that you can do to address the Essential Messages. These strategies are written in SMART objective format (Specific, Measurable, Achievable, Results-Oriented, Timely). Mark an "X" in up to three boxes next to the ideas that you think you would MOST like to emphasize in your daily practice for each Essential Message. If you would like to create your own strategy, using SMART objective format, you are welcome to do that as well. *[Allow 7 minutes to complete the activity. After activity is done ask 2-3 people to share one strategy they think they would like to implement starting tomorrow.]*

BREAK

Facilitator Notes
Module 2: Development, IDD & Trauma

SLIDE 31

Module 2: Development, IDD & Trauma

- In the last Module we discussed why a Toolkit that addresses the needs of children with IDD who have had traumatic experiences is important.
- In this Module, you will learn about typical milestones that occur throughout a child's development and how IDD can detour those milestones.

SLIDE 32

Module 2: Learning Objectives
What Will I Learn Today?

After completing today's training, you should be able to do the following:

1. Define IDD and types of disabilities.
2. Discuss developmental tasks across typical development.
3. Describe how IDD and traumatic experiences may disrupt typical development.
4. Describe how IDD and traumatic experiences may disrupt typical development.
5. Identify the areas in which children's functioning is affected by IDD & subsequent adaptations that must be made.

SLIDE 33

What is Development?

TRAINER TIP: *Read the slide.*

SLIDE 34
Types of Development

- Development is more than just about physiology or biology—It is also about who you are as a whole person. Development includes **biological**/physiological processes (e.g., motor skills) as well as **cognitive** development (problem solving, conceptual understanding, language acquisition), **psychosocial** development (social, **personality** development, emotional development, self-concept & identity formation), and **moral** development.

SLIDE 35
Development

- For the purposes of this training, we're going to focus on 5 specific domains of development which correspond with the *Bayley Scales of Infant and Toddler Development (3rd Edition)*, a test that measures the mental, motor and behavior development of infants from one to 42 months of age: Language, Motor, Cognitive, Social Emotional & Adaptive. These are the categories used to describe development for the first few years of life in the Bayley Scales, but have applicability across the lifespan.
- **Language Development**
  - Expressive: how well a child communicates using sounds, gestures, or words
  - Receptive: how well a child recognizes sounds and how much your child understands spoken words and directions
  - Pragmatic communication includes nonverbal and social communication.
- **Motor Development** refers to how the body increases in skill and performance.
  - Gross motor development: how well a child can move his or her body; the development of our large muscle groups (e.g., walking, running, skipping).
  - Fine motor development: how well a child can use his or her hands and fingers to make things happen; the development of the precise use of our muscles (e.g., tying shoes, fastening buttons, using zippers).
- **Cognitive development** is learning the skills of understanding, memory and concentration, along with learning to communicate with family, friends, and community. Intellectual/cognitive development includes communication/speech development.
  - In the early years, cognitive development is focused on orienting, attention, and basic problem solving. Around school-age, cognitive development focuses on functions related to neurodevelopment and intelligence.

- **Neurodevelopment** includes 8 different functions:
  1. Attention
  2. Memory
  3. Language
  4. Spatial Ordering (perceiving, remembering, creating, organizing, thinking on a higher plane)
  5. Sequential Ordering (arranging things in a particular/fixed order)
  6. Motor (gross, fine, graphomotor/writing, oromotor/speaking)
  7. Higher Thinking (problem solving, critical thinking, rules, creativity)
  8. Social Thinking

- **Social/Emotional** is the development of a child's identity, self-image, relationships (including attachment), behavior patterns, accompanied with learning the skills to live in society as a member of the community. Social/emotional development includes behavioral development.
  - Sensory development is included in Social Emotional development in the 1st year of the Bayley, but sensory preferences and sensitivities remain important throughout the lifespan.
  - The ability to regulate feelings and behavior, self-regulation, is part of social emotional development.
- **Adaptive functioning** is the ability to adapt to various demands of normal daily living.
  - Communication: speech, language, listening, and nonverbal communication skills
  - Academic/intellectual skills
  - Self-direction/self-control: following directions, making choices
  - Leisure activities
  - Social skills: getting along, using manners, assisting others, recognizing emotions
  - Community: interest in activities outside the home
  - Home living: helping adults with household tasks and taking care of personal possessions
  - Health & safety: knowledge of basic health activities & physical dangers (e.g., wearing a coat outside, being careful around a hot stove)
  - Self-care: activities such as eating, toileting and bathing
  - Motor: locomotion & manipulation of objects

SLIDE 36
Traits vs. Skills

- It is important to understand that there is a distinction between traits and skills, particularly when discussing IDD. While children with IDD may have genetic conditions and specific aspects of their development that cannot be changed (i.e., traits), skills can still be learned.

SLIDE 37
Federal Definition of Intellectual and Development Disabilities

P 9

- Knowing the federal definition of IDD is important because it impacts the available services for children with IDD and families. Clinicians and families need to know how to navigate the system.
- The definition emphasizes functional limitations in adaptive behaviors, or understanding of the impact of the disability on functioning.
  - Reviewing areas of functional limitations suggests areas for accommodation and/or skill building.
- See the **Supplemental Materials** section for the full definition.

SLIDE 38
Types of Disability

PP 10-13

TRAINER TIP: *Let participants know that going into detail for every different type of disability is beyond the scope of this Toolkit. However, for the purposes of recognizing that there are a wide variety of types of disability, with varying impacts on adaptive functioning, we will review some types. Also recognize that these categories are somewhat arbitrary and there is overlap between categories. This highlights the complexity of disabilities; they are often not easy to categorize.*

- There are many different types of disability. Although this Toolkit will not cover every different type of disability, we will review different types for the purposes of recognizing that there is a range of issues that children with IDD face. Additionally, there are different assessment strategies and strategies for accommodation and/or skill building associated with different types of IDD.

  1. Genetic
  2. Neuromotor
  3. Mental health (e.g., ADHD, depression, anxiety)Individuals with Disabilities Education Act (IDEA) uses the term "emotional disturbance" to describe students with emotional or behavioral disorders.
  4. Neurological (e.g., autism, epilepsy)
  5. Intellectual
  6. Sensory (e.g., vision & hearing, sensory-integration—balance, sense of touch)

Disabilities are best understood as a combination of biological, psychological and social factors, rather than purely in biological terms.

- It is helpful to use a biopsychosocial model when thinking about the categorization of disabilities: biological, psychological (thoughts, emotions, behaviors) and social (socio-economical, socio-

environmental, cultural) factors, all play a significant role in human functioning in the context of disabilities. Disabilities are best understood as a combination of biological, psychological and social factors, rather than purely in biological terms.

- So we recognize that these categorizations that we are offering here are somewhat false, as most disabilities don't "cleanly" fit into just one category. However, for the purposes of this training, it gives us a place to start with thinking about different types of disabilities.
- The **Supplemental Materials** section has more information on specific types of disability, with links to videos and additional resources.
- Let's briefly take a deeper look at each of these domains of disability.

SLIDE 39
Genetic Disabilities

- A genetic disability is a disability caused by an absent or defective gene or chromosomal aberration. Examples include:
  - **Down Syndrome**. Down Syndrome (trisomy 21) is a common cause of Intellectual Disability (ID) in children. Co-occurring medical symptoms (such as congenital heart defects, respiratory and hearing problems) and a variety of mental health issues (including anxiety and ADHD) may be seen.
  - **Fragile X Syndrome**. Fragile X Syndrome is the most common inherited cause of ID in children. Many people with Fragile X also have autism. It is caused by a mutation on the X chromosome. Boys, who have only one X chromosome, are usually more affected than girls.
  - **Prader-Willi Syndrome**. Prader-Willi Syndrome (PWS) is a non-inherited genetic disorder usually characterized by mild ID, overeating, obesity, and obsessive-compulsive behavior.
  - **Angelman's Syndrome**. Angelman's Syndrome is a genetically-based developmental disorder characterized by ID, speech impairment, happy demeanor, and unusual motor behavior.
  - **Williams Syndrome**. Williams Syndrome (WS) is a genetic disorder usually characterized by low intellectual functioning, unusual strengths in spoken language and sociability, hyperactivity, impulsivity, and inattention.

Note that not all genetic disabilities are inherited by a parent.

  - **Phenylketonuria**. PKU is an inherited metabolic disorder than can cause severe ID if the metabolic problem is not addressed adequately through a very restrictive diet.
- Note that not all genetic disabilities are inherited by a parent. For example, Down Syndrome is a non-inherited disability which is caused by a mistake in how the chromosomes segregate, causing a child to inherit an extra chromosome 21.

SLIDE 40
Neuromotor Disabilities

- A neuromotor disability is a disability caused by damage to the central nervous system (the brain and the spinal cord). The resulting neurological impairment limits muscular control and movement. Examples include:
  - **Cerebral Palsy** is a condition marked by impaired muscle coordination (spastic paralysis) and/or other disabilities, typically caused by damage to the brain before or at birth. Children with cerebral palsy may have typical intellectual functioning, though some have learning difficulties to varying degrees. They are also at risk for seizures and co-occurring mental health concerns.
  - **Spina Bifida** is a congenital defect of the spine in which part of the spinal cord and the membranes that enclose it are exposed through a gap in the backbone. It often causes paralysis of the lower limbs, and sometimes intellectual disability or learning disability.
  - **Traumatic Brain Injury** (TBI) is s a nondegenerative, noncongenital insult to the brain from an external mechanical force, possibly leading to permanent or temporary impairment of cognitive, physical, and psychosocial functions, with an associated diminished or altered state of consciousness.

A neuromotor disability is a disability caused by damage to the central nervous system (the brain and the spinal cord).

SLIDE 41
Mental Health Disabilities

PP 14-15

- A mental health disability is a disability caused by a mental health condition with a severe impact in functioning.
- It is important to note that more and more research supports that many conditions that traditionally have been thought of as mental health diagnoses have a neurological basis (e.g., autism).
  - The increasing recognition of many mental health diagnoses as having a neurological basis demonstrates the challenge of labeling conditions as categorically "mental health disorders." We will discuss neurological disabilities (e.g., autism and ADHD) in greater detail on the next slide.
- Some education and many mental health systems use the term serious emotional disturbance (SED) to categorize students with disabilities whose issues include a mental health diagnosis (e.g., ADHD, depression, anxiety). This categorization can lead to eligibility for services through an Individualized Education Plan (IEP) process.
  - It is important to understand that diagnostic labels can be both helpful and harmful. Diagnoses can be helpful for the purposes of establishing service eligibility, a treatment strategy, or insurance reimbursement. However, diagnoses can also be harmful when they are used to

exclude individuals from receiving services or to merely label an individual as opposed to considering the manner in which it describes how an individual interacts with the world.

- Individuals with Disabilities Education Act (IDEA) uses the term "emotional disturbance" to describe students with severe emotional or behavioral problems. It is a special education category for students whose behavioral or emotional responses are not typical. For more information on IDEA, see the **Supplemental Materials** section.

It is important to understand that diagnostic labels can be both helpful and harmful.

SLIDE 42
Neurological Disabilities

- This domain is quite broad and includes neurological and medical conditions. However, we are not saying that every child with a medical issue has a disability. For example, many children have epilepsy that is controlled with medication and does not impact their functioning or ability to participate in most, if not all, activities as their peers. For some children though, medical conditions have a severe impact in limiting functioning, and are thus considered a disability. Examples include:
- In the IDD world, **autism** is not considered a mental health condition, although Autism Spectrum Disorder is a diagnosis in DSM-V. It is a disability; children with autism don't "recover." We teach them how to manage the world they live in. Additionally, autism is often characterized by ID, sensory conditions, language deficits, and inappropriate social behaviors. Again, It's important to note that diagnostic labels can be helpful and harmful, as we discussed on the last slide.
- **ADHD** is increasingly recognized as a condition that is due to neurodevelopment *immaturity*, and as a developmental delay, a neurological condition. However, it is still considered a mental health diagnosis and is reimbursed as such.
- **Fetal Alcohol Syndrome (FAS)** is caused by maternal alcohol consumption during pregnancy. FAS is characterized by ID, hyperactivity, slow physical growth and (sometimes) craniofacial anomalies.

Not every child with a medical issue has a disability.

- **Lead poisoning** occurs when lead builds up in the body, often over a period of months or years. Even small amounts of lead can cause serious health problems. Children under the age of 6 are especially vulnerable to lead poisoning, which can severely affect mental and physical development.
- **Epilepsy** is a neurological condition in which a person has repeated seizures over time. Seizures are episodes of disturbed brain activity that cause changes in attention or behavior.

SLIDE 43
Intellectual Disability

- Intellectual disability includes significant limitations in ***both*** intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.
- **Intellectual functioning** refers to general mental capacity, such as learning, reasoning, problem solving, and so on. One way to measure intellectual functioning is an IQ test. Generally, an IQ test score of around 70 or below indicates a limitation in intellectual functioning. In some cases, an IQ score up to 75 might also indicate a limitation if an individual has significant challenges in his/her adaptive functioning.
- **Adaptive behavior** is the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives.
  - **Conceptual skills**—language and literacy; money, time, and number concepts; and self-direction.
  - **Social skills**—interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.
  - **Practical skills**—activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.
- Source: American Association on Intellectual and Developmental Disabilities

SLIDE 44
Sensory Disabilities

- A sensory disability is a disability that involves any of the five senses.
  - It can also impact kinetics, the awareness of one's body in space.
- It generally refers to a disability related to hearing, vision, touch, smell and/or taste.
- Sensory-integration issues result from the brain's inability to integrate certain information received from the body's five basic sensory systems. Those who have sensory integration challenges may be unable to respond to certain sensory information by planning and organizing what needs to be done in an appropriate and automatic manner. The following are some signs of sensory integration problems:
  - Oversensitivity to touch, movement, sights, or sounds
  - Underreactivity to touch, movement, sights, or sounds
  - Tendency to be easily distracted
  - Social and/or emotional problems
  - Activity level that is unusually high or unusually low

- Physical clumsiness or apparent carelessness
- Impulsive, lacking in self-control
- Difficulty in making transitions from one situation to another
- Inability to unwind or calm self
- Poor self concept
- Delays in speech, language, or motor skills
- Delays in academic achievement

Sensory-integration issues result from the brain's inability to integrate certain information received from the body's five basic sensory systems.

- Vision impairment/blindness and hearing impairment/deafness are also examples of sensory disabilities.

SLIDE 45
Traumatic Experiences & IDD Can Disrupt Development

- Developmental levels often are not smooth across the domains of development.
  - IDD-specific issues may alter presentation of traumatic stress symptoms.
- Both IDD and traumatic experiences can disrupt development by impacting the acquisition of these key developmental tasks.
- This is not to say that trauma stops development completely, but it can act as a risk factor and slow down a developmental trajectory that has already been slowed down by the IDD.
- Child traumatic stress reactions will vary depending on the developmental stage. For example, the reaction of a three-year-old child is going to be very different from the reaction of an eleven-year-old girl. The developmental stage is impacted because children who have been exposed to trauma expend a great amount of energy responding to, coping with, and coming to terms with the traumatic event. The energy that is spent doing so reduces a child's capacity to explore their environment and to master age-appropriate developmental tasks. When a child experiences a traumatic event, the child must allocate resources to survival that are normally dedicated to growth and development. The longer the traumatic stress goes untreated, the farther the children stray from appropriate developmental pathways.
  - Children with IDD may have reduced receptive and expressive language skills which result in their greater reliance on behaviors as a way to communicate fear, terror, feeling unsafe.
- Let's take a closer look at how IDD and traumatic experiences may impact responses at different developmental levels.

SLIDE 46
Development Across the Lifespan

- As we introduced in Module 1, Erikson's theory of psychosocial development is a lifespan model that describes key psychosocial conflicts that an individual is tasked with across different points of development.
- We will now take a closer look at key developmental tasks for each stage of development.

SLIDE 47
IDD & Trauma in Early Childhood

- Given the differences in developmental levels, the trauma symptoms that children present will vary depending on the age and developmental level of the individual child. The symptoms in young children are different than those in school-aged children and so forth.
- There are certain periods—special times during the brain's development—when it is most open to certain kinds of learning and development. When trauma occurs during one of these periods, it may show itself in specific ways.
- Early childhood—about birth through the preschool years—is crucial for the development of brain pathways that:
  - Help children process what they see and hear
  - Enable children to recognize, analyze, and respond to emotional cues
  - Enable children to become attached to their primary caregiver—the person on whom they depend for survival
- As infants develop into young children, they begin to develop **greater independence** and their **capacity to assess danger** increases as they test new limits.
- Young children also begin to develop a sense of self (e.g., their **self-concept & self-esteem**), which gains greater momentum during middle childhood.
- Early childhood is also a time of great **motor** and **language** development.
- Some examples that may be present in infancy and early childhood are strong physiological and sensory reactions, responding to sound by blinking, quieting, crying, startling; quieting to voice, touch; self-regulating through swaddling; crying when hungry or uncomfortable; expressing confusion about assessing threats and finding protection. Young children may engage in regressive behaviors. Bed-wetting is a common symptom.
- Given their lack of understanding of cause and/or effect, most young children will blame themselves for the traumatic event.

- One of the most significant developmental milestones of young children is developing secure attachments with caregivers and as such, trauma symptoms often manifest in significant issues with attachment.
  - Reject contact and avoid being touched
  - Be confused about what's dangerous and whom to go to for protection, particularly if the trauma was at the hands of a caregiver
  - Be clingy and resist being separated from familiar adults or places where they feel safe
- When traumatic experiences are the result of interactions with parents/caregivers, the impact on development, at this young age, can be particularly significant, especially on developmental tasks like attachment.
- **For a young child with IDD** who has a traumatic experience:
  - The child may have more difficulty calming down after being scared; it may be harder to reassure him/her.
  - The child's ability to communicate verbally may be limited by the IDD. Even for typical children, there has been a myth that young children do not experience trauma because they are too young to know. This type of bias may be heightened for a child with IDD.
  - The child may use behaviors such as withdrawal or become less responsive as a way to communicate fear, terror and feeling unsafe.
  - Developmental gains are at times more fragile for children with IDD. Following a traumatic experience loss of recent gains (e.g., toilet training) may be more dramatic and/or they may lose even older gains.
  - Additionally, young children with IDD may experience and express more negative affect, have more trouble interacting with peers, may become more aggressive, may develop new fears, and may be more behavioral/emotionally dysregulated (especially infants.).
- *[Ask participants for additional ideas.]*

SLIDE 48
IDD & Trauma in Middle Childhood

- During the school years, the brain starts building the pathways that help children do more conscious, rational processing of their experiences. This growth enables them to:
  - Manage fears, anxieties, and aggression
  - Focus their attention on learning and solving problems
  - Control their impulses and manage their physical reactions to perceived dangers
- Children in middle childhood loosen their rigid views on such topics as fairness and consequences. They develop **higher-level thinking about "right" and "wrong"** as moral development increases. They move from "I could get in trouble for this" to "I am behaving because it is the right thing to do."

A school-aged child with IDD who has a traumatic experience, may have reduced receptive and expressive language skills that make it difficult to communicate about ongoing intrusive thoughts and images.

- Middle childhood is also the time when children **begin to develop a greater self-concept**. Their evaluation of themselves is what determines their self-esteem. They can evaluate their physical, emotional, academic and social skills and make judgments about whether they are good or not at certain tasks. They may say " I am a good student but a bad athlete." They develop this self-awareness by comparing themselves to their peers and with input from parents, teachers and other caregivers.
- During middle childhood, children receive emotional support, learn different points of view and share their thoughts and feelings with newfound friends. Children begin to test their communication and social interaction skills with their friends. Children learn how to manage their emotions and get along with others through friendships. The **development of friendships** is highly dependent on a sense of mutual trust. Usually friendships at this age are between children of the same gender.
- The trauma symptoms that may be present in school-aged children include:
  - Attention problems relate to
    - ✓ Experiencing unwanted and intrusive thoughts and images
    - ✓ Sleep disturbances
  - Becoming preoccupied with frightening moments from the traumatic experience
  - Replaying the traumatic events in their minds in order to figure out what they could have prevented or how it could have been different
  - Developing intense, specific new fears linking back to the original danger
  - Alternating between demonstrating shy/withdrawn behavior and unusually aggressive behavior
  - Becoming so fearful of recurrence that they avoid previously enjoyed activities
  - Having thoughts of revenge
- **A school-age child with IDD** who has a traumatic experience:
- May have reduced receptive and expressive language skills that make it difficult to communicate about ongoing intrusive thoughts and images about the traumatic experience. Additionally, this preoccupation may heighten learning challenges, which may have already needed additional attention because of the IDD.
  - May become withdrawn and quiet at some times and have tantrum-like behavior that is out-of-sync with their age (much like a younger child) at other times
  - May lose developmental gains they achieved years ago (e.g., toilet training)
  - May have even more exaggerated difficulties with precision learning (e.g., math), that require focused attention
  - May have difficulty with peer relationships and vulnerability to persistent teasing, bullying/ isolation from peers
- *[Ask participants for additional ideas.]*

SLIDE 49
IDD & Trauma in Late Childhood & Young Adulthood

- During adolescence, the brain continues to build connections and pathways that enable young people to:
  - Think abstractly
  - Imagine the future and anticipate and consider the consequences of their behaviors
  - Make realistic appraisals of what's dangerous and what's safe
  - Alter their current behaviors in order to meet their longer-term goals
- The major task facing adolescents (13 to 18) and into young adulthood is to create a stable **identity** and to become a mature and productive adult. Adolescent development relies upon what is learned in the course of relationships and through past experiences. Youth use these experiences and beliefs as a basis upon which to define themselves, make judgments about the world, and develop relationships with others.
  - A child's identity is oftentimes an extension of one's parents and family. During adolescence, an individual recognizes his or her uniqueness and ability to define oneself as separate and different from one's background. An adolescent may have the opportunity to redefine his or her own identity. Mentors and role models can be very important to this process.
- At no other time since birth does an individual undergo such rapid and profound **physical changes** as during early adolescence. Puberty is marked by sudden rapid growth in height and weight. Also, the young person experiences the emergence and accentuation of gender-specific hormonal and physical development. The young person looks less like a child and more like a physically and sexually mature adult. The effect of this rapid change is that the adolescent often becomes focused on his or her body.
- **Peer interaction** hits the peak of importance in adolescence. It progresses in later adolescence and early adulthood as the depth and quality of these relationships mature based on common values and beliefs. If an adolescent is able to make friends and belong to a mutually supportive peer group he or she is likely to successfully adjust in other areas of development. Peers play the primary supportive role for emotional development. They help youth to begin to define who they are and how they fit into the broader community.

An adolescent with IDD who has a traumatic experience during late childhood or young adulthood may experience decreased motivation for learning.

- And of course, **romantic interest** becomes more prominent.
- Before adolescence, children's thinking tends to be concrete. They need concrete examples of situations and problems before they can solve them.
- During adolescence, young people can understand **abstraction**; they can consider more hypothetical situations, and "what-ifs."

- During the course of adolescence, individuals
  - Establish adult **vocational goals**; join the workforce
  - Develop independent identities
  - Begin to plan for and imagine their futures
  - Forge new relationships with mentors and role models
- Adolescents who have experienced trauma may:
  - Feel that they are weak, strange, or childish, or "going crazy" because of their bouts of fear or exaggerated physical responses. This may lead them to even further isolation, anxiety, and depression.
  - Feel embarrassed by their fears or exaggerated physical responses
  - Believe they are unique and alone in their pain and suffering
  - Feel intense anger
  - Experience low self esteem and helplessness
  - Engage in aggressive or disruptive behavior
  - Experience sleep disturbances marked by late-night studying, television watching, or partying
  - Engage in reckless or self-destructive behaviors, such as drug or alcohol abuse, cutting themselves, or having unprotected sex
  - Have difficulty imagining or planning for any kind of future, instead "living in the moment" without regard to consequences
- **An adolescent or young adult with IDD** who has had a traumatic experience:
  - May feel that learning and planning for the future is more difficult
  - May feel increased/longer dependence on parents/caregivers
  - May become demoralized and feel defeated, particularly about the future
  - May feel even more "different" from others & worry about feeling less accepted by peers
- *[Ask participants for additional ideas.]*

SLIDE 50
Introducing…

PP 13-19 20 MIN

TRAINER TIP: *This slide is an Activity. Assign each table a case. Participants will use two handouts for this activity,* ***Putting It Into Practice—Case Vignettes: Trauma, IDD & Development****. Consult Appendix A of the Facilitator Guide, Learning Objectives for Case Vignettes, for ideas for discussion points to highlight during the discussion following this activity.*

- I am getting ready to introduce you to six different children, adolescents, and young adults. We're going to keep referring back to these youth through the training.
- Meet Ivana– she is an 18-month infant who was adopted at birth from Russia.
- Suzie is a 4 year-old living with her family in San Francisco.
- Joshua is a 6 year-old who lives with his family on the upper west side of Manhattan.
- Steven is 10 and lives with his family at Camp Pendleton in San Diego.
- Jacqueline is 16 and lives with her grandmother in Laredo, Texas.
- And Justin is a 19 year-old living with his foster parents in Detroit.
- Ask participants to read the case that their table has been assigned and then complete the **Putting It Into Practice—Case Vignettes: Trauma, IDD & Development** handout. *[Allow participants 20 minutes to complete the handout and share ideas at their tables. Ask each table to share one takeaway from their discussion with the whole group.]*

LUNCH

SLIDE 51
Developmental vs. Chronological Age

- Once a provider knows the developmental level of the child, he/she can contextualize behaviors at that developmental level. But recognize that some of the child's behaviors, interests and preferences may be closer to the chronological age, so "developmental age" is only a rough guide.
- Therefore, considering a child's developmental age alone may not be as useful a descriptor as often thought because some of the child's behaviors may be at the chronological age.

SLIDE 52
Living with IDD: A Child's Perspective

15 MIN

TRAINER TIP: *This is an Activity slide. You will need 10 large pieces of paper posted up around the room. You can use large sticky post-it pads or just tape large pieces of paper on the walls. Each of the 10 pieces of paper should have one of each of the domains of functioning written on the top (i.e., one piece of paper will say "Self-Care," another will say "Communication," and so on). Pass out several normal size post-it pads to the table. Each person will need several post-its and a pen. You are going to ask the participants to think about* ***how living with IDD affects these different domains of functioning****. They are going to write brief answers on their post-its and stick them to the relevant domains. Give participants 7 minutes to wander around and place post-its throughout the room. If it looks like they need more time feel free to give them more time, but wrap up around the 10 minute mark. You will then ask one participant to stand at each large piece of paper and read off the post-its and ask if there is anything they would add.*

- It's important to consider the experience of LIVING with IDD, not just "having IDD," both from the child and family's perspective. This raises the question, what is the adaptive functioning of a child with IDD? Disabilities can impact functioning in a number of domains (as shown on the slide).
- We're going to do an activity. You'll notice that there are large pieces of paper on the wall with these domains listed. Take a few of the post-its that are out on our tables. You will need a handful. What we want you to do is think about how living with IDD effects the quality of life for the child and the family. Imagine children with various disabilities. What are some ways their daily functioning is impacted in these areas? Think about the challenges that come with each of these areas and start to think about how you, as a provider, can help support children with IDD. When we give the word, take time to walk around the room with your post-its and think about how IDD affects each of these areas. Write brief responses on your post-its and then stick that response on the large paper it corresponds to. For instance, living with IDD may inhibit the way children can ask for help. So you would write, "unable to ask for help" on your post-it and stick it on the Communication paper. We're going to give you several minutes to walk

around and think of responses. *[Allow participants 7-10 minutes to walk around and apply their post-its to the pieces of paper. Once everyone has finished or time runs out, ask a volunteer to stay at each of the large pieces of paper for a report out.]*

- Let's quickly go around the room and see what people came up with. [*Call on each of the volunteers standing to select 3-5 post-its on their large piece of paper to read out to the group. After all the volunteers have finished reading, ask if there's anything the group would like to add.]*
- Summarize the activity with three points:

1. Quality of life is extremely important to children with IDD and their families. As a provider you always need to keep in mind how you can support/increase the quality of life for your clients.
2. Consider how each of these domains of functioning may be impacted by traumatic experiences. The ideas we would come up with probably would not be very different from what we already have on our post-its.
3. As a provider, you will be/or are planning trauma-informed support, services and treatment. Everything we've just read off will have to be taken into account when you draw up service plans for your clients. We will be discussing this more in Module 5.

SLIDE 53
Living with IDD: A Family's Perspective

TRAINER TIP: *Nora Baladerian's book,* ***A Risk Reduction Workbook for Parents and Providers****, may be useful to highlight as an example of a resource that parents may find helpful to reference for guidance on how to develop a risk reduction plan for children with IDD. Specifically, she outlines ideas for what to talk to children about before, during and after a traumatic event.*

- Families of children with IDD are also "living with IDD."
- What other challenges or concerns do you think they face? Take 2 minutes to discuss with the person next to you. *[Allow 2 minutes for discussion].*
- Here are some ideas.

SLIDE 54
Essential Messages

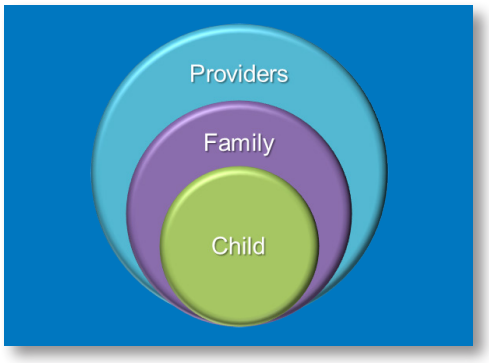
- As a recap, let's review the Essential Messages that we just discussed in Module 2.

3. Recognize a child's developmental level and how IDD and traumatic experiences are affecting his/her functioning.
4. Utilize a developmental lens when making meaning of a child's traumatic experiences & responses.

SLIDE 55
What Can a Provider Do?

P 20 7 MIN

TRAINER TIP: *This is an Activity slide, which will recur at the end of each Module. This is the opportunity for participants to reflect on their own practice and think concretely about what they can enhance or do differently, based on the information that was just presented to them in Module 2. Participants will be given a checklist to fill out to help guide their reflections. Emphasize to participants that if they feel that the options are too clinically focused they should create strategies that are relevant to their role.*



- Here are some things that you as a provider can do to address the concepts that we just discussed in Module 2. Think about the child you identified at the end of Module 1 who connects you to this work. What can help that child and other children with IDD who have experienced trauma? Let's take a few minutes to think about what you can do specifically in your role and at your organization to address any one of these points.
- Pull out your handout titled, ***Action Planning: Essential Messages 3 & 4***. This is your opportunity to think about how you are going to implement the ideas that we just discussed in Module 2, into your daily practice, as soon as you get back to your office. You will see that the handout outlines specific strategies for things that you can do to address the Essential Messages. These strategies are written in SMART objective format (Specific, Measurable, Achievable, Results-Oriented, Timely). For example, "Over the next three months, I will review my caseload and identify at least three children with IDD and identify developmental 'detours' that have already occurred. I will review these areas each time I meet with these children." Mark an "X" in up to three boxes next to the ideas that you think you would MOST like to emphasize in your daily practice for each Essential Message. If you would like to create your own strategy, using SMART objective format, you are welcome to do that as well. *[Allow 7 minutes to complete the activity. After activity is done ask 2-3 people to share one strategy they think they would like to implement starting tomorrow.]*

Facilitator Notes
Module 3: Traumatic Stress Responses in Children with IDD

SLIDE 56

Module 3: Traumatic Stress Responses in Children with IDD

- In the last module we learned about some developmental models, typical milestones that occur throughout a child's development, and how IDD can detour those milestones.
- This module focuses on how traumatic experiences generally affect development, and how they can specifically effect children with IDD. We'll do this by delineating the 12 Core Concepts for understanding traumatic stress responses in children.

SLIDE 57

Module 3: Learning Objectives
What Will I Learn Today?

After completing today's training, you should be able to do the following:

1. Define child traumatic stress and Posttraumatic Stress Disorder (PTSD).
2. Describe the 12 Core Concepts for understanding traumatic stress responses in children and families.
3. Identify how traumatic experiences and their responses affect children with IDD.

SLIDE 58 (OPTIONAL)

ReMoved

6 MIN

TRAINER TIP: *Optional Video.* *This may be a good place to show a video that depicts the impact of trauma. You might choose to show clips from the film, ReMoved. The 6 minutes of selected clips (from the trailer) may be an impactful way to introduce responses to traumatic experiences by highlighting the thoughts and feelings she is experiencing, how her behavior may be a reaction to trauma reminders, and the hope that she can recover and will be loved. Remind participants about self-care: provide a warning that the clip may be upsetting.*

- *ReMoved* follows the emotional story through the eyes of a young girl taken from her home and placed into foster care.
- This video, ***ReMoved***, will start us off on our discussion of trauma by starting with the child's voice. Let's listen to her experience of trauma. While we don't know whether or not she has an IDD, we do know that many children in the foster care system have IDD.
- Source: https://www.youtube.com/watch?v=lOeQUwdAjE0
- Available for purchase: www.removedfilm.com

SLIDE 59
How would you define Child Traumatic Stress?

TRAINER TIP: *This is a quick introduction to see how participants define traumatic experiences. It allows you to take the temperature of the group to find out where they are on the topic.*

- How would you define child traumatic stress? Just shout out whatever comes to your mind.

SLIDE 60
What is Child Traumatic Stress?

PP 16-18

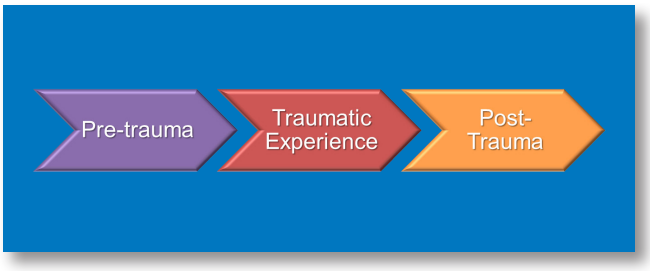
- Child traumatic stress occurs when children and adolescents **personally experience or witness** a real or perceived threat to emotional or physical well-being. It is important to distinguish child traumatic stress from stress or anxiety.
- According to mental health experts, a traumatic experience is different from an everyday upsetting event in important ways:
  - A traumatic experience **threatens our lives and bodily integrity** (i.e., bodily violation, violence, abuse, rape). Witnessing a traumatic event that threatens the life or physical security of someone we love can also be traumatic. This is particularly important for very young children as their sense of safety depends on their perceived safety of their attachment figures. What might be potentially traumatic for a six month-old baby may not necessarily be traumatic for a nine year-old child. A child's perception of what is traumatic varies by age and developmental stage.
  - Traumatic experiences can initiate **strong emotions and physical reactions** during its course that persist afterwards. A person may feel terror, horror, or fear. Hearts may pound, vomiting or loss of bladder or bowel control, feeling stuck in a nightmare, or even passing out can occur.
- Children who experience an inability to protect themselves or lacked protection from others to avoid the consequences of the traumatic experience may also feel **overwhelmed** by the intensity of physical and emotional responses.
- The body and mind respond with a sense of how serious the event is to the child, and this intensity registers in the child's body and mind.

- A child's response to an event is based, in part, on the child's **perception of the danger** and lack of protective action.
- When children have a traumatic experience, they react in both **physiological** (heart rate may increase, sweat, feel agitated, hyperalert, become emotionally upset) and **psychological** ways.

- Children who suffer from child traumatic stress are those children who have been exposed to one or more traumas over the course of their lives & develop **reactions that persist** and affect their daily lives after the traumatic events have ended.
  - Traumatic reactions can include a **variety of responses**, including intense and ongoing emotional upset, depressive symptoms, anxiety, behavioral changes, difficulties with self-regulation, forming relationships/attachments, loss of previously acquired skills/regression, attention and academic difficulties, nightmares, physical symptoms such as difficulty sleeping and eating, and aches and pains, among others.
  - Children who suffer from traumatic stress often have these types of symptoms when **reminded** in some way of the traumatic event.
  - At no age are children immune to the effects of traumatic experiences; even infants and toddlers can experience traumatic stress.
  - Although many of us may experience reactions to stress from time to time, when a child is experiencing child traumatic stress, these reactions **interfere with his/her daily life** and ability to function and interact with others.
  - For children who do experience traumatic stress, there are a wide variety of potential consequences.
  - The way that traumatic stress manifests will vary from child to child and will depend on the child's age and developmental level.
- Some of these children may develop ongoing symptoms that are diagnosed as post-traumatic stress disorder (PTSD), which we will discuss in further detail later in this Module.
- Not every child who experiences a traumatic event will develop symptoms of child traumatic stress. Whether or not a child does, depends on a range of factors (e.g., availability of supportive attachment figures, history of previous trauma exposure).
- See the **Supplemental Materials** section for the NCTSN ***What is Child Traumatic Stress?*** Fact Sheet.

SLIDE 61
Types of Traumatic Experiences

- Remember back in Module 1 when we discussed how the type of traumatic event and age at which it occurred is important to understand its effect? For example, trauma inflicted by the caregiving system early in life is different from a teenager experiencing a car crash who has lived with a nurturing family.



Keep that in mind as we begin talking about the different types of traumatic events that children can experience. Additionally, remember that responses to traumatic experiences are affected by life experiences prior to, during, and after the experience(s).

- **Single traumatic experiences** can range from experiencing an earthquake and being trapped, caught in a robbery or being shot, being in a car serious car accident, witnessing violence or getting threats to actual injury.
  - It's important to take note of disasters or related experiences because children and adolescents with IDD may be particularly impacted by the physical nature of their disability. For example, if a child is in a wheelchair, their ability to respond or react in the face of a disaster will be affected and that ability to react (or not) may influence how he/she responds to the traumatic experience.
- **Experiences that occur together**. For example, a child might be in a home where he/she is a witness or is a victim of both physical and emotional abuse.
- **Experiences that can extend over time** are situations that can occur repeatedly over long periods of time. These experiences call forth a range of responses, including intense feelings of fear, loss of trust in others, decreased sense of personal safety, guilt, and shame. An example of this might be living in a dangerous community or being a victim of ongoing abuse.
- **Experiences that are a mixture** may be multiple and varied and includes things like living in a domestic violence situation, experiencing a car accident, and having a medical procedure.
- When a traumatic event involves someone whom the child depends on for caregiving assistance and safety, it creates additional challenges.
- Additional examples of traumatic experiences that children with IDD may face:
  - **Medical Trauma**. Given frequent physical co-morbidities that may require procedures and invasive physical examinations that the child may have difficulty understanding and communicating his/her feelings about, medical trauma may be an important factor to consider when working with children with IDD.
  - **Systems Trauma**. Children with IDD and their families may experience repeated discrimination and alienation by the systems that are supposed to be providing them with services.

SLIDE 62
Core Concept 1: Complexity

PP 19-24

TRAINER TIP: *Remind participants of the timeline (pre-trauma, during the traumatic experience, post-trauma).*

- The 12 Core Concepts for understanding traumatic stress responses in children and families have been developed by the NCTSN to describe characteristics of traumatic experiences and their intersection with key areas such as development, family & caregiving systems, protective factors and culture. We will now review each Core Concept to understand traumatic stress responses and how these responses may manifest in children with IDD. See the **Supplemental Materials** section for a brief summary of all 12 Core Concepts.

- The 1st Core Concept for understanding traumatic stress responses in children and families is: **Traumatic experiences are inherently complex**.
  - There are **many different moments** within a single traumatic experience. A child may have to contend with threats to themselves and others. The mind and body of a child are very active.
  - The child **continually appraises** the danger, emotionally responds, physically reacts, and considers what is needed to gain protection or to end the threat.
  - A child's reactions are **active and dynamic** in response to the moment by moment changes as the event unfolds.
  - These reactions are influenced by the child's developmental level, prior trauma and loss experiences, culture, and the child's personal strengths and vulnerabilities.
  - The way the child views and responds to the world is often built upon successive layers of expectations about danger, safety, and protection that emerge from a history of multiple trauma and loss experiences.
  - Appreciating the complexity of a child's experience enhances a fuller understanding of the child that is often lost when the child is simply categorized by the type of experience he or she has undergone.
- **For a family & child with IDD**:
  - These moment-to-moment reactions can be even more complex due to physical, cognitive or communicative limitations that impact the range of protective actions that were possible during the traumatic experience.
    - ✓ **Cognitive limitations** can alter the understanding and meaning of what is happening. Again understanding the functional limitations of the child helps to determine the potential impacts.
  - Children with intellectual disabilities are vulnerable because they **may not appraise danger in the same way that** a child without IDD may appraise danger. They may act more like a younger child.
    - ✓ They may require more supervision or require someone to protect them from danger.
    - ✓ Sequencing events (during the traumatic experience) may be challenging.
    - ✓ Emotional labeling may be challenging
    - ✓ How they conceptualize what happened to them could be limited.
  - Children with physical disabilities may be able to understand the danger but might not be able to do anything about it. Physical limitations might not allow them to be as responsive as they would imagine or want.
  - Children with other disabilities (e.g., sensory or rare conditions) may have different challenges that impact their ability to appraise danger.
  - The question for providers is how does someone with this set of disabilities understand what happened to them?
  - Another question that may come up for parents/caregivers is how much to explain to the child about what happened to them & protect them from future danger (e.g., if they don't understand what sexual abuse is, how much do they explain)?

SLIDE 63
Core Concept 2: Life Experience

TRAINER TIP: *Tie the concept in this slide back to the ecological model. The point is to think about how trauma & IDD impact the child, family, provider, and community circles.*

- The 2nd Core Concept for understanding traumatic stress responses in children and families is: **Trauma occurs within a broad context that includes children's personal characteristics, life experiences, and current circumstances**.
  - Childhood trauma occurs within the broad ecology of a child's life that is composed of both child-intrinsic (or internal) and child-extrinsic (or external) factors.
  - **Child-*intrinsic*** factors include personal attributes and resources such as age, temperament, developmental attainment, learning from prior experiences, prior exposure to trauma, and prior history of mental health conditions.
  - **Child-*extrinsic*** factors include the surrounding ecology of family, school and community, including their current functioning, available resources and level of threat.
- This chart is a good depiction of the child-intrinsic and child-extrinsic factors related to IDD and trauma. Both of these sets of factors impact how a child will respond to a traumatic experience.
  - These factors help shape children's expectations regarding danger, protection and safety.
  - It is important to identify and address these internal and external factors to be able to understand children's traumatic experiences and facilitate their recovery.=
- **For a family & child with IDD**:
  - A provider needs to understand the surrounding circumstances of the family & child with IDD (the ecology of the child), as opposed to only knowing what happened (i.e., what the traumatic experience was). For the child with IDD, life experience refers to how IDD affects his/her every day life. It is important to understand the impact of the traumatic experience within that context. For example, a question might be—what's involved in this child's care, related to his/her IDD?
  - Let's re-visit the ecological model. Where do IDD and traumatic experience(s) fit in these circles? The core concept, Life Experience, is emphasizing the need to focus on how IDD and traumatic experiences affect each of the circles—the child, family, provider and community context.
  - What is the current context? (prior to the trauma) Examples:
    - ✓ For a child who is in a wheelchair and lives in a violent neighborhood, the context of an assault is different than if the child lived in a safe neighborhood.
    - ✓ A child with autism may not read social cues correctly and misinterpret a benign event or miss one that was damaging.
    - ✓ Some children with severe intellectual delays may have a difficult time seeing their experiences as separate from their parents/caregivers (e.g., what is happening to my mom

is happening to me). Young children also experience the world through their caregiving relationships, and are profoundly affected and threatened by witnessing trauma experienced by a parent/caregiver.

- ✓ For infants and very young children with IDD their vulnerability to the impact of traumatic exposure increases as they often depend on their caregiving environment/system to protect them and make meaning of traumatic experiences. They are particularly vulnerable when the parents' protective, comforting, or regulating capacities are impaired. Alternatively, when parents/caregivers are sensitive, attuned, and responsive, they can help buffer the effects of trauma on the child.

- What events or experiences are they dealing with now? What life experiences have they had related to their IDD in the past? How might those past experiences (e.g., being bullied) be influencing their understanding of the current traumatic experience?

SLIDE 64
Core Concept 3: Reminders & Adversities

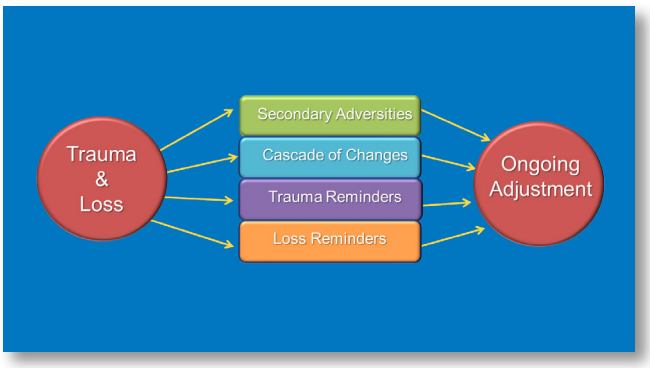
TRAINER TIP: *This Toolkit specifically identifies "loss" separately from trauma due to the NCTSN's view that loss is often overlooked when describing traumatic experiences. However, recognize that loss in and of itself does not constitute a traumatic experience.*

- The 3rd Core Concept for understanding traumatic stress responses in children and families is: **Traumatic events often generate secondary adversities, life changes, and distressing reminders in children's daily lives**.

  - Traumatic experiences can set in motion a cascade of changes in children's lives that can be challenging and difficult. These can include changes in where they live, where they attend school, who they're living with, and their daily routines. They may now be living with injury or disability to themselves or others. There may be ongoing criminal or civil proceedings.

  - Traumatic experiences leave an aftermath of reminders that may persist for years. These reminders are linked to aspects of the traumatic experience, it's circumstances, and its aftermath.

  - Children may be reminded by persons, places, things, situations, anniversaries, or by feelings such as renewed fear or sadness. Physical reactions can also serve as reminders, for example, increased heart rate or bodily sensations.



  - Identifying children's responses to trauma and loss reminders is an important tool for understanding how and why children's distress, behavior, and functioning often fluctuates over time.

  - Trauma and loss reminders can reverberate within families, among friends, in schools, and across communities in ways that can powerfully influence the ability of children, families, and

communities to recover. Addressing trauma and loss reminders is critical to enhancing ongoing adjustment.

- **For a family & child with IDD:**
  - Children with IDD and families may have already had to find a way to cope with secondary adversities related to the IDD.
  - Trauma may add to these significant secondary adversities related to IDD (e.g., more appointments, criminal proceedings, child welfare involvement/investigations). The combination can further tax already stressed coping resources of the family & child.

SLIDE 65
Trauma Reminders

TRAINER TIP: *Have a participant read the quote.*

"For the longest time we couldn't understand why Billy was always acting out and seemed unhappy on our holiday trips to the mountains. We didn't realize that the smell of wood burning in a fire was a reminder of the the ski trip to Colorado, during which Billy was assaulted."

- A trauma reminder is anything that an individual unconsciously attaches to the memory of a trauma. It can be anything from a place, smell, sound, thing, or person. Individuals can have the same responses/reactions to a reminder as the actual traumatic event itself.
- It is not uncommon for typically developing children or children with IDD to have difficulty communicating their distress in words when they encounter trauma reminders. Instead, the distress is expressed through behavior, sometimes, as in Billy's situation, through disruptive behavior. This illustrates an important idea, **"all behavior is communication."**

BREAK

SLIDE 66
Core Concept 4: Wide-Ranging Reactions

- The 4th Core Concept for understanding traumatic stress responses in children and families is: **Children can exhibit a wide range of reactions to trauma and loss**.
  - Children can remain fearful, anxious, sad, guilty, ashamed, and related behaviors. Given the complexity of trauma and loss experiences, children may manifest their distress through a range of reactions including post traumatic stress, dissociation, grief, depression, separation anxiety, among others. These reactions may include bodily sensations and physical symptoms like nausea, stomach aches, head aches, muscle tension, and fatigue. In the immediate aftermath, there are various reactions.
  - Over time, children's distress reactions may decrease, or instead consolidate into a formal mental health disorder.
  - The challenges of secondary adversities and life changes may intensify the children's reactions to traumatic experiences. They also may contribute an important secondary source of distress for children that may lead to additional worries, demoralization, depression, behavioral problems, and substance abuse. In addition, children with pre-existing mental health conditions may be especially vulnerable to experiencing an exacerbation or renewal of symptoms.

  - It is important to understand how these reactions and symptoms may take a toll on children's daily functioning and developmental progression. It is also important to take into account how a child's developmental level may influence children's expression of distress. The disturbances in development can include loss of developmental achievements, disturbances in their ability to establish relationships, disturbances in developing sense of self, disturbances in physiological stress-response system, disturbances in affect expression and regulation, interference with readiness to take on new developmental tasks, or premature and precocious behavior that introduces significant risk.
- **For a family & child with IDD:**
  - Traumatic experiences need to be understood in light of a child's IDD. For example, the responses of the child may look more like what a provider would expect from a younger child.
  - A child with IDD may be trying to communicate about his/her traumatic experience, yet a provider may see it as a "behavior challenge" related to the disability. If the provider only tries to manage the behavior and doesn't address the underlying traumatic experience, it could exacerbate the child's trauma response.
    - ✓ In children with very limited communication, distress may be signaled by exacerbation of an old behavior (like screaming or head-banging) or increase of a non-specific behavior (like pacing).
  - Trauma & loss experiences can interact with other behaviors (e.g., aggression) that disrupt fragile gains in impulse control that had already been made. For example, perhaps the aggression was a behavior that was being successfully addressed and then the traumatic experience occurred and re-ignited the behavior. Children may lose hard-won gains in functioning, which can feel devastating for children, as well as families.

SLIDE 67 (OPTIONAL)
Who We Are

5:22 MIN

TRAINER TIP: ***Optional Video.*** *This may be a good place to show a video that illustrates some of the content of the Core Concepts. Clips of* ***Ask Us Who We Are*** *can be used to highlight the wide range of responses children and adolescents have to traumatic experiences.*

- ***Ask Us Who We Are*** is a documentary film focused on the challenges and extraordinary lives of youth in foster care. The film is a reflection on loss and the search for belonging and finding family. Although the film highlights the heartbreak that many foster care youth carry with them as they move through their lives, the documentary also reveals the tremendous strength and perseverance that grows out of their determination to survive and thrive.
- Available through Kingdom County Productions, www.kingdomcounty.org/shop.
  Note: this video must be purchased.

SLIDE 68
Traumatic Stress & PTSD

P 25

- There are a common set of reactions frequently seen in children and adolescents—as well as parents—who have had a traumatic experience.
- When these post-traumatic stress reactions continue longer than one month, in a set pattern, they can meet criteria for PTSD.
- Although the presentation may vary by age and developmental stage, children and adolescents can develop PTSD.
- Let's take a closer look at the criteria.
- See the handout in the **Supplemental Materials** section for the DSM-5 criteria for PTSD.

SLIDE 69
Criteria for PTSD

- First, in order to meet criteria for a diagnosis of PTSD, there must be a certain degree of **exposure** under direct threat or injury, or witnessing threat/injury, including sexual abuse.
  - This includes learning about serious threat, injury or violent death to a family member or close friend.
  - Recent studies suggest that exposure to emotional abuse is experienced as life-threatening by young children and may also produce PTSD symptoms.

- Second, details of the traumatic event **recur**, including pictures in the mind and physical sensations.
  - There may be nightmares, distressing images, re-enactment play or other images of danger to self and family.
  - Children and adolescents may experience intense emotional distress in response to reminders or may experience renewed physical reactions.
  - In both cases, it may be hard for the child to calm down afterwards.
- Third, children and adolescents may try to stay away from thoughts or feelings about what happened or may try to **avoid** trauma reminders or the people, places, and activities that are associated with what happened.
  - Children do not always have a choice about where to go, who to be with or hearing what others are talking about. They may be frustrated in their efforts to avoid painful experiences that can then show up as tantrums, withdrawal, constriction of play and affect, or what seems like oppositional behavior.
- Fourth, the danger, violence and seeming lack of protection can cause children and adolescents to **expect** other bad things to happen, to judge something to be wrong with themselves or to expect that parents/others will not be able to protect them in ways they know they need.
  - Children may also continue to feel intense and difficult emotions like fear, anger, guilt, shame, horror and betrayal.
  - In the face of what happened, they may feel less invested in their own lives and future planning and markedly lose interest in or stop participating in, significant activities.
  - One of the difficulties for children and adolescents is that they may feel alone with their experienced private feelings and this may lead them to feel different from others. These feelings of difference may lead them to feel detached and estranged.
  - One of the serious consequences of trauma is that it may then be more difficult to have happy, satisfying or loving feelings.
- Fifth, traumatic experiences can take a toll on how the body continues to **react**. The sense of needing to be on alert and ready for danger can lead children to have irritable behavior (i.e., fussiness in babies) and angry outbursts, including verbal and physical aggression toward people or objects.
  - Rather than avoid situations, children and adolescents may act more fearless and engage in thrill-seeking or reckless behaviors.
  - This may include self-destructive behavior.
  - Conversely, they may be on the lookout for danger (e.g., hypervigilance) that takes away from being relaxed or being able to attend to enjoyable activities. This may also cause problems in concentration that make learning, homework or other focused activities difficult.
  - Children and adolescents are especially vulnerable to sleep disturbances.
    - ✓ These may not just include anxieties or worries before bedtime that make it difficult to fall asleep, but quickness to awake to outside noises, restlessness during sleep and other sleep problems.

Accurate diagnosis is essential to identifying appropriate treatment.

- ✓ Children and adolescents who are not getting restful sleep are often irritable and have trouble learning.

- Traumatic experiences lead to **impairments** in functioning in children and adolescents. For example, important relationships with parents, siblings and friends may be affected, or they may experience difficulties in school performance, behavior and other developmental goals.
  - These may include loss of prior developmental gains (talking, bowel training etc.), derailments in adolescent development that can lead to changes in motivation and ambitions.
- Accurate diagnosis is essential to identifying appropriate treatment. We will talk more about treatment in Module 5.

SLIDE 70
Traumatic Stress and Other Diagnoses

- Posttraumatic stress and grief reactions can develop into other mental health conditions and diagnoses over time, including posttraumatic stress disorder (PTSD), separation anxiety, and depression.
- Children's posttrauma distress can also exacerbate preexisting mental health conditions including depression and anxiety. Awareness of the broad range of children's potential reactions to trauma and loss is essential to competent assessment, accurate diagnosis, and effective intervention.
- However, sometimes children are misdiagnosed due to lack of understanding of trauma responses. They may be mislabeled with diagnoses of Attention-Deficit/Hyperactivity Disorder, Oppositional Defiant Disorder, or Bipolar Disorder because of the difficulties with mood and behavior regulation that these children often display.
  - Misdiagnoses generally do not capture the full extent of the developmental impact of trauma.
  - The symptoms leading to misdiagnoses may in fact be a child's reaction to a trauma reminder, which can result in withdrawn, aggressive, reckless or self-injurious behaviors.
- For young children with developmental disabilities who have experienced trauma there are additional challenges in assessing their symptomatology:
  - Symptoms may change as developmental functions emerge
    - ✓ Need to use different measures at different developmental stages depending on the child's functional level
  - Necessity of caregiver report
    - ✓ Different caregivers may not agree
  - Current diagnostic criteria may not be appropriate for young children.
    - ✓ DSM-5 is trying to address this challenge with a new developmental subtype of PTSD which describes differences in symptoms for preschool children versus older individuals.
- Competent assessment is critical for accurate diagnosis and effective intervention.
- Assessment needs to be developmentally-guided, relationship-based, grounded on an ecological approach (assess functioning of child, caregiver, child-caregiver relationship, ecology in which relationship exists, experiences and response to trauma) and strengths-based.

SLIDE 71
Core Concept 5: Danger & Safety

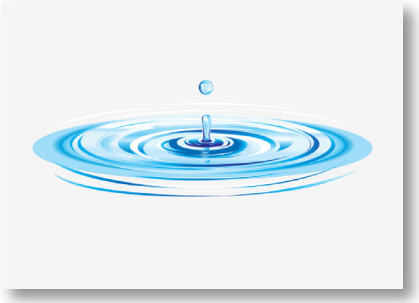
- The 5th Core Concept for understanding traumatic stress responses in children and families is: **Danger and safety are primary concerns in the lives of traumatized children**.
  - Issues of danger, protection and safety are paramount considerations in dealing with children and families who have had traumatic experiences. Children, adults, and society expect and depend on a protective shield to keep them safe from danger. When traumas occur, everyone experiences a failure in this protective shield.
  - Trauma and loss experiences often create uncertainties about the likelihood of future danger, harm, and loss. It can take children, parents, other caregivers, and the community a significant amount of time to restore a sense of safety.
  - Practical steps are important to restoring safety and protection, but restoring confidence in a protective shield can take much longer. These concerns can effect ongoing perceptions of threat and behavioral responses often elicited by traumatic reminders.
- **For a family & child with IDD**:
  - In the aftermath of a traumatic experience, children and parents/caregivers alike want to have a protective shield against danger. Traumatic experiences challenge children & families' sense of a protective shield against danger and restoring confidence in safety can take quite some time. Oftentimes, traumatic experiences threaten the ability to trust in the protective shield.
    - ✓ The child is looking for parents to provide a protective shield.
    - ✓ Families may be looking for the community to provide a protective shield.
  - During that time, children & caregivers may be concerned about whether they will appropriately recognize future dangers, know what to do and physically be able to protect themselves.

SLIDE 72
Core Concept 6: Caregiving Systems

TRAINER TIP: *Remind participants of the ecological model.*

- The 6th Core Concept for understanding traumatic stress responses in children and families is: **Traumatic experiences affect the family and broader caregiving systems** *(as a stone thrown in a pond creates a ripple, some bigger & closer, others smaller & further).*

- Children are deeply embedded within their families, schools, and communities. Caregiving systems are challenged in two interconnected ways.



  - ✓ First, these systems are challenged by how to respond to the changes in children brought about by children's traumatic experiences, losses, and adversities.
  - ✓ Second, parents, other caregivers, family members, friends, school personnel, and members of the community are often also changed by traumatic experiences and losses. They bring their own life experiences, sets of reactions, and concerns that can further complicate their ability to support and respond to traumatized and bereaved children. Level of exposure, extent of loss, frequency of reminders, and cascade of adversities all have an effect on the capacity of caregiving systems to function and meet their own needs as well as those of traumatized children and their families. It is important to understand the types and amount of caregiving resources and how these resources have been affected.
- Again, we know that traumatic experiences impact the entire ecological system and vice versa. The entire ecological system impacts a child's posttrauma response.

- **For a family & child with IDD:**
  - Parents/caregivers may feel devastated by what happened to their child. They put so much effort into protecting their child, and yet the traumatic experience still occurred. It may be especially hard for them to find trauma treatment and trauma-informed systems because of the child's disability.
  - The child, family and caregiving systems may feel overwhelmed by the specific needs of a particular child and family, which are over and above the needs related to the child's IDD that they may already have. This may impact the sources of support that are made available.

SLIDE 73
Core Concept 7: Protective Factors

TRAINER TIP: *For the purposes of this Toolkit, we are not making as great a distinction between protective and promotive factors, instead focusing on protective factors more generally.*

- The 7th Core Concept for understanding traumatic stress responses in children and families is: **Protective and promotive factors can reduce the adverse impact of trauma**.
  - Protective factors buffer against the harmful effects of traumatic experiences and their aftermath.
    - ✓ The child brings intrinsic qualities (e.g., temperament) to their efforts to adjust and adapt. An anxious child may too quickly jump to catastrophic thoughts in the face of a reminder and have difficulties accepting reassuring information whereas another child may seek and use outside support to calm themselves. Children may draw upon prior successes in adapting to hardship.
    - ✓ Protective factors are also external to the child. For example, while it may take time to restore confidence in a protective shield, often appropriate and timely protective steps can be taken

to protect against future dangers that are essential to addressing a child's concerns. With an enhanced sense of safety and security, children can benefit more from a host of promotive factors.

- **Promotive factors** are inherent resources in the child and within the child's physical environment that help propel children towards healthy development, including the capacity to adapt to challenging or changing circumstances. These constitute the beneficial ingredients that foster the social, physical, and emotional growth of a child. Children thrive in enriching learning and emotional environments with stable and engaged teachers, parents, and mentors. Replenishing and reinforcing these external resources helps children to cope with their post traumatic and grief reactions to handle adversities and to reinvest in their own developmental progression.

- **For a family & child with IDD**:
  - Children with IDD may already be experiencing multiple adversities related to IDD. The child and parents/caregivers may feel that protective factors have been spent buffering the effects of the IDD. Providers' reassurance that strategies for addressing the affects of traumatic experiences can be adapted for children with IDD by enhancing protective factors is essential.
  - Children with IDD may be limited in their ability to seek support when they need to, make their needs known, and/or have others take protective action on their behalf. These are all protective factors that are potentially less immediately available to some children with IDD. Providers can work with parents/caregivers to enhance attachment and create a safe and healing environment.

SLIDE 74
Core Concept 8: Development

- The 8th Core Concept for understanding traumatic stress responses in children and families is: **Trauma and posttrauma adversities can strongly influence development.**
  - Child development represents a complex process of acquiring sets of competencies and attaining achievements that unfold across multiple domains over time.
  - Traumatic events and outcomes can injure and put important developmental areas at risk as they mature through early childhood to late adolescent or adulthood. These injuries have great variability and can cause developmental interruptions, delays, cessations, regression, and precocious developmental acceleration.

Don't just think symptoms—think development.

  - The traumatic event and consequences of the event cause a hit on developmental processes as they occur at key times in the child's life. We want to be able to help the child to thrive and make use of their developmental potential. Ongoing developmental concerns color traumatic experiences.

- According to developmental level, children may have concerns about separation and attachment, psychosexual issues, physical appearance and injury, peer acceptance or rejection, and implications for their future. Because traumatic experiences may happen during significant developmental transitions, children and adolescents can experience them as putting these important developmental goals and achievements in jeopardy.

- **For a family & child with IDD**:
  - Traumatic experiences may result in a significant setback in developmental progress, which was already challenged by IDD.

SLIDE 75
Core Concept 9: Neurobiology

- The 9th Core Concept for understanding traumatic stress responses in children and families is: **Developmental neurobiology underlies children's reactions to traumatic experiences.**
  - The brain is active and always taking in information from the world around us, putting us on alert for danger and calculating the best actions to take in response.
  - The danger apparatus of the brain that helps orchestrate the responses of the body (e.g., endocrine, immune, and motor) goes through a slow maturation from early childhood through young adulthood. Children's capacities to appraise and respond to danger are linked to an evolving neurobiology that consists of brain structures, neurophysiological pathways, neural circuits, and neuroendocrine systems.
  - The human brain matures slowly from requiring intensive protective supervision to gradual increases in the ability to protect oneself and others, while always at risk for inexperience.
  - There is a complex "danger apparatus" of the brain and body that is always working to keep us safe, protected, and ready for action. The danger apparatus is highly complex and underlies how we appraise danger, emotionally and physically react, and select protective actions.
    - ✓ Beyond flight or fight, when it comes to danger, trauma, and loss, the human brain is a social brain. It is set up to seek prevention, protection, effective intervention, and rescue, for example, by evoking and responding to cries of distress. The danger apparatus has to learn something from what happened. The biology of "remembering" includes opportunities for reappraisal, reframing, and consideration of additional protective interventions. It also includes learning how to live in a world filled with reminders.
  - The brain offers ways to temper the danger responses, especially those evoked by reminders, while learning to adapt to future dangers and challenges.
  - From early childhood through young adulthood, the brain matures in order to help achieve successive developmental tasks. At any point in time, trauma can cause changes in neurobiology that can affect children's capacities to negotiate the world around them, function at their best and move forward in their development. It is important to understand how adaptive responses can become maladaptive responses over time and adversely affect relationships, behavior, and health.

- **For a family & child with IDD:**
  - Neuromotor & physical aspects of IDD may affect how the danger apparatus appraises & responds to danger.

- ✓ Some of the maturation of the nervous system that gives us more of the danger apparatus may not be as advanced in children with IDD. Additionally, a traumatic experience can further impact maturation.
- ✓ At the same time, problems like sleep disturbances may really compromise daytime attention and functioning.

- Cognitive limitations can alter the understanding and meaning of what is happening. Again understanding the developmental perspective of the child helps to determine the potential impacts.

- Other IDD-specific features may alter presentation of traumatic stress symptoms. For example hearing, vision, communication and movement problems affect behavior.

SLIDE 76
Core Concept 10: Culture

- The 10th Core Concept for understanding traumatic stress responses in children and families is: **Culture is closely interwoven with traumatic experiences, response, and recovery.**
  - Considerations of culture are important to understanding all of the Core Concepts. Children and families must be understood from the vantage point of multiple cultural influences, whether the society at large, their local community, specific group affiliations, or that of their own individual family. Culture shapes meanings, beliefs, and expectations that govern attitudes, norms, behaviors, and social interactions.
  - Culture can be used as a lens for understanding the ways in which children and families experience and express distress, disclose personal information, exchange support and seek help.
  - Culture is used to navigate life's challenges, including how to interpret danger, protection and safety; to consider the personal consequence of a traumatic experience; and to pursue paths towards recovery. Shame, guilt, acceptance and exclusion are all infused with culture.
  - Human response to death provides one of the strongest examples of the power of culture in terms of bereavement, mourning and grief. A cultural group's experiences with historical or multigenerational trauma can serve as a vivid backdrop to current trauma and loss experiences, enhance a sense of shared experience with prior generations, add to expectations regarding self, others and social institutions, and offer motivation to share in the pursuit of protective interventions and justice.

- **For a family & child with IDD:**
  - Families and children with IDD are often part of multiple cultural identities and communities, including disability communities, which may impact the experience and expression of trauma. All of these cultural identities are important to understand as part of the parent and child's response to what happened and being able to recognize strengths and sources of support.
  - It is important to recognize that sometimes cultural values and beliefs are congruent with our own and other times they are not.

SLIDE 77

Core Concept 11: Social Contract

- The 11th Core Concept for understanding traumatic stress responses in children and families is: **Challenges to the social contract, including legal and ethical issues, affect trauma response and recovery.**
  - Because child traumatic stress involves a failure or violation of the protective shield for children and families, there is an inseparable link to the wider social contract. Whether one is speaking about child maltreatment, domestic violence, community or school violence, natural disaster, or catastrophic accidents, questions always arise about prevention and protection, effective intervention, timely and appropriate rescue, quality medical or mental health attention, and sufficient resources to promote recovery. These issues involve legal, moral, and ethical considerations.
  - There are laws and regulations governing every level of society to ensure safety and protection. There are social institutions such as law enforcement, judicial systems, child welfare systems, schools, disaster preparedness and response agencies, and many others that are integral to upholding the social contract.
    - ✓ It is common for traumatized children and their families to interface with one or more of these social institutions. These interactions can make a strong impression on the child.
    - ✓ The nature of these interactions as well as the child and family's response to them are both important to understanding the overall circumstances surrounding traumatic experiences or loss.
    - ✓ Children's understanding of the social contract and the role of social institutions undergoes its own developmental course and may need to be re-visited over time as it effects the child's sense of morality, attitudes regarding parenting, prosocial values, and citizenship.

  - Enforcing, restoring, and upholding the social contract is part of the reparative work of intervening in the aftermath of traumatic stress.
- **For a family & child with IDD:**
  - The report of a traumatic experience by a child with IDD may not be believed.
  - Children with IDD and families may encounter the false belief that children with IDD can't/don't experience trauma.
  - Families often have had to deal with many social agencies, school etc., in order to obtain services to meet needs related to their child's IDD.
  - Families of children with IDD may have experienced significant disparities in access to services and supports. They may have experienced lost income, painful choices (e.g., food vs. co-pays) and unresponsive private insurance and public systems.
  - Their views of fairness, justice and the roles and responsibilities of society, already challenged by IDD, may be compounded by traumatic experiences.

- What we're really talking about here is the impact of the community in the ecological model that we've now discussed many times. How do the attitudes of the community and broader society about disability, such as stigma impact the child with IDD and family? How does it affect their ability to seek support and justice?

SLIDE 78
Core Concept 12: Provider Distress

TRAINER TIP: *Remind participants of the ecological model. The provider is embedded in a system with the child and family, and therefore may experience many aspects of what the child and family experience.*

- The 12th Core Concept for understanding traumatic stress responses in children and families is: **Working with trauma-exposed children and their families can be extremely rewarding.**
  - However, this work can also evoke distress in providers for a number of professional and personal reasons. Providers must confront disturbing situations involving children and families affected by trauma and loss experiences, a multitude of adversities and violations of the social contract including failure of the protective shield.
  - In order to be the most helpful, providers must be open to hearing everything the child has to say. They are privy to some of the most intense, horrific, and difficult child experiences. This can be emotionally demanding and challenging.
  - From an individual to an organizational level, it is important to ensure a sense of professional accomplishment rather than induce a sense of futility, bolster self care that prevents emotional exhaustion, and to receive organizational support that values the work and addresses the many practical issues that otherwise can cause serious professional distress.

  - Working with traumatized children and families can evoke strong personal memories of trauma and loss related experiences that must be properly attended to and respected.
  - Any individual who works directly with traumatized children and adolescents is vulnerable to the effects of trauma-referred to as **secondary traumatic stress** or compassion fatigue-being physically, mentally, or emotionally worn out, or feeling overwhelmed.
  - Practicing self care requires an active effort on the part of the clinician and/or service provider. To do so, entails developing strategies for prevention and intervention. These include but are not limited to psychoeducation, clinical supervision, ongoing skills training, self-care groups, implementing sways to evaluate secondary stress, caseload adjustments, and referrals to outside sources of help.
- **For a parent/caregiver of a child with IDD:**
  - Parents/caregivers may have had an initial grief response to learning about their child's IDD, sometimes followed by recurring sorrow if their child with IDD falls behind or is left out.

- Traumatic experiences may re-evoke concerns about the vulnerability of their child and their own inability to protect the child from harm.
- At the same time, hearing about their child's traumatic experience and coping with responses may evoke strong personal memories & feelings for parents & caregivers, as well.
- We'll talk more about this in Module 6 when we discuss ways to promote provider self-care.

SLIDE 79
Responses to Traumatic Experiences

PP 13-18 & 21-22 | 20 MIN

TRAINER TIP: *This slide is an Activity. Assign each table a case, that is different from the one they looked at in Module 2. Participants will use two handouts for this activity,* ***Putting It Into Practice—Case Vignettes: Responses to Traumatic Experiences****, and the* ***12 Core Concepts Description****. Assign each table a case to review. Consult Appendix A of the Facilitator Guide, Learning Objectives for Case Vignettes, for ideas for discussion points to highlight during the discussion following this activity.*

- Ask participants to read the case that their table has been assigned and then complete the ***Putting Into Practice*** handout. *[Allow participants 20 minutes to complete the handout and share ideas at their tables. Ask each table to share one takeaway from their discussion with the whole group.]*

SLIDE 80
Essential Message

- As a recap, let's review the Essential Message that we discussed in Module 3.

5. Recognize that in the aftermath of trauma, understanding traumatic stress responses is the first step in helping children regain their sense of safety, value and quality of life

SLIDE 81
What Can a Provider Do?

P 23 | 5 MIN

TRAINER TIP: *This is an Activity slide, which will recur at the end of each Module. This is the opportunity for participants to reflect on their own practice and think concretely about what they can enhance or do differently, based on the information that was just presented to them in Module 3. Participants will be given a checklist to fill out to help guide their reflections. Emphasize to participants that if they feel that the options are too clinically focused they should create strategies that are relevant to their role.*

- Here are some things that you as a provider can do to address the concepts that we discussed in Module 3. Think about the child you identified at the end of Module 1 who connects you to this work. What can help that child and other children with IDD who have experienced trauma? Let's take a few minutes to think about what you can do specifically in your role and at your organization to address any one of these points.
- Pull out your handout titled, ***Action Planning: Essential Message 5***. This is your opportunity to think about how you are going to implement the ideas that we just discussed in Module 3, into your daily practice, as soon as you get back to your office. You will see that the handout outlines specific strategies for things that you can do to address this Essential Message. These strategies were written in SMART objective format (Specific, Measurable, Achievable, Results-Oriented, Timely). Mark an "X" in up to three boxes next to the ideas that you think you would MOST like to emphasize in your daily practice for this Essential Message. If you would like to create your own strategy, using SMART objective format, you are welcome to do that as well. *[Allow 5 minutes to complete the activity. After the activity is done ask 2-3 people to share one strategy they think they would like to implement starting tomorrow.]*

SLIDE 82
Evaluation of Learning: Day 1

PP 25-26 5 MIN

TRAINER TIP: *This evaluation of learning will be completed at the end of Day 1 & Day 2.*

- Pull out your handout titled, ***Post-Training Evaluation: Day 1***. Please complete it and turn it in before you leave for the day.
- Thank you! See you tomorrow!

Facilitator Notes: Day 2
Module 4: Child & Family Well-Being & Resilience

SLIDE 1

The Road to Recovery: Supporting Children with IDD Who Have Experienced Trauma

Welcome to Module 4 of the *Road to Recovery* training—Child & Family Well-Being & Resilience.

SLIDE 2

Module 4: Child & Family Well-Being & Resilience

- In the last Module we learned about how traumatic experiences affect development generally, and children with IDD specifically, by delineating the 12 Core Concepts for understanding traumatic stress responses in children.
- This Module will help you understand the role of protective factors, such as a secure attachment and a healing/protective environment, in enhancing child & family well-being & resilience, and how to provide practical tools and support for parents/caregivers.
- Module 4 primarily focuses on how enhancing family well-being and resilience, ultimately enhances child well-being, resilience and recovery.

SLIDE 3

Self-Care Alert!

- As was true yesterday, the topics we are going to cover may be upsetting to some of you. They may bring up difficult memories of clients that you've helped. Your heart goes out to these kids and families. They are vulnerable. It's bad enough when a child without disabilities has a traumatic experience, but we have even more intense and strong responses when a child with disabilities has a traumatic experience. It evokes feelings of unfairness and injustice, and enhances our desire to protect. We feel that society should pay even more attention to vulnerable people and those we believe need to be protected.
- You may have friends or yourself have a child with IDD. The material in this training may bring up feelings and thoughts related to your experiences.

- Please feel free to step out of the room at any time during the presentation.
- Alternatively, it is okay to stay in the room, even if you are feeling emotional.
- We strongly encourage you to take care of yourself not only during this training but also in your work setting. We will talk more about the importance of self-care in Module 6.

SLIDE 4
Module 4: Learning Objectives
What Will I Learn Today?

After completing today's training, you should be able to do the following:

1. Explore the impact on parents/caregivers on learning about their child's traumatic experience.
2. Explain strategies for strengthening protective factors to enhance child and family well-being, resilience and recovery.
3. Describe frameworks for promoting a healing and protective environment in order to create a safe and meaningful life for children.
4. Identify family-informed, child-centered planning techniques to help children realize their hopes and dreams.

SLIDE 5
The Challenge for Parents/Caregivers

- Raising a child can strain a relationship, even without IDD or trauma. Parents/caregivers may disagree on child-rearing issues, some small, some large. They **may feel inadequate** because they don't know what to do.
- With IDD and trauma, parents may vary in terms of their acceptance and/or feelings of **grief and loss** related to the IDD and trauma and the way they respond. They may not fully understand the functioning level of the child or may have expectations of "recovery" or progression that may not be realistic.
- These differences in response can cause **stress and strain on relationships** and create conflicts.
- The essential act of listening to the traumatic experiences of children and dealing with the aftermath of traumatic experiences, including their behavior, thinking, and emotional responses may take an emotional toll that can compromise parents'/caregivers functioning and interfere with limit-setting/ routines and result in over-protection. Parents/caregivers might also relax routines and limits because they feel their child has "suffered enough," which can end up being more unsettling for the child.

- Providers should recognize the potential impact of traumatic experiences of children with IDD on their parents/caregivers. Parents may have **anticipatory anxiety** about safety, protection, how to ensure that their children will be happy and healthy etc.
- They may also experience **secondary traumatic stress** due to hearing about their child's traumatic experience(s), their role in failing to protect, and/or because it is a reminder of their own trauma history. For example, it is not unlikely that for many young children and their parents/caregivers, the traumatic experience(s) involved both the child and the parent and so the child and parent might serve as a traumatic reminder for each other. Intervention requires the reparation of the child-parent relationship, as this will be the vehicle for recovery.

- Families of children with IDD may have **increased stress due to ongoing needs** of children that may continue into adulthood.
- Providers can support questions by acknowledging sources of stress and concern (e.g., financial stress), providing anticipatory guidance and answering questions.

SLIDE 6
Potential Impact on Siblings

- Each child's personality and temperament play an important role in their response toward a sibling, including one with a disability. Although both positive and negative feelings exist in all sibling relationships, McHale and Gamble (1987) conclude, "…for school-age children and young adolescents, these relationships tend to be more positive than negative in their feeling tone. Furthermore, children with disabled siblings appear to have more positive and fewer negative behavioral interactions than do those with non-disabled siblings…." These positive aspects include higher levels of empathy and altruism, increased tolerance for differences, increased sense of maturity and responsibility, and pride in the sibling's accomplishments (Powell & Ogle, 1985).
- Elementary school-aged children may feel embarrassed or ashamed as they recognize differences between their sibling and someone else's brother or sister. They may worry about "catching" or developing the problem, and they may feel guilt because they themselves do not have a disability. They may also feel protective and supportive of their sibling, and this may result in conflicts with peers.
- Some siblings struggle to understand the behavioral and emotional problems of the sibling with IDD. They may be asked to accept treatment by their sibling that feels mean or annoying on a regular basis. They may also be frustrated by different sets of rules and consequences for the sibling with IDD.
- Young adults may have future-oriented concerns. They may wonder what will become of their brother or sister with a disability. They may also be concerned about how the people they socialize with, date, and later marry will accept the brother or sister with a disability. Additional issues faced by young adults may include genetic counseling when planning their own families, and coping with anxiety about future responsibilities for the brother or sister with a disability or illness.
- Parents/caregivers should share information with siblings about the traumatic experience or responses so that siblings aren't wondering/imagining what's going on.
- Siblings benefit from groups to talk with others facing similar issues.

- Although these points about the potential impact on siblings seems to focus on the impact of having a sibling with IDD, they also apply to having a sibling who has had a traumatic experience. Hearing about a traumatic experience of a sibling may create anxieties and worries in their siblings and reinforce their perspective that they need to be helpful and responsible. Alternatively, traumatic experiences may result in even more time having to be spent with the child with IDD, which may be resented.

- Source: http://www.ldonline.org/article/6054

SLIDE 7
Protective Factors

TRAINER TIP: *Remind participants of the risk/protective factors & ecological frameworks that we introduced in Module 1.*

- Remember our brick wall? In addition to protective factors that are more central to the parents are those that include characteristics of the child, family, community, and culture. We introduced some of these protective factors in Module 1 and just showed you our brick wall. Let's take a closer look at the actual bricks.
- A key question is how do we *increase* and *enhance* protective factors? How do we get these bricks strong? To do this you have know what can help strengthen them. To add to our metaphor, the question becomes, how do we add mortar to build, re-build and strengthen the bricks, the protective factors?
- Let's look at four specific areas where we can strengthen protective factors:
  - **Individual**
  - **Family**
  - **Community**
  - And **Culture**

How do we <u>increase</u> and <u>enhance</u> protective factors?

- What are some ideas for increasing and enhancing protective factors in each of these four areas: individual, family, community and culture?
  - For example: one way to increase protective factors in the community area is by educating the community about trauma and value including children with IDD in services, support and treatment.
- This discussion should remind you of the ecological framework that we introduced in Module 1. Essentially, we are highlighting protective factors in each of these circles.

SLIDE 8
Enhance Family Well-Being and Resilience

- How do we build up a wall of protective factors around families?
- Enhancing the family's well-being and resilience is an essential part of enhancing the child's well-being, resilience and recovery.
- Families are a critical part of both protecting children from harm and enhancing their natural resilience. However, families may find it difficult to be protective if they have been affected by trauma, and they may need help and support in order to draw on their natural strengths.
- Additionally, in situations in which parents/caregivers are the source of the trauma, they will need more intensive interventions, in addition to education and support, especially if they have trauma histories of their own.
- Providing trauma-informed education and services to parents and other caregivers enhances their protective capacities, thereby increasing the resilience, safety, permanency, and well-being of the child.
- Providers should recognize that caregivers themselves may have trauma histories or experience secondary traumatic stress and provide them with appropriate trauma-focused support and interventions.

SLIDE 9 (OPTIONAL)
Enhance Child Well-Being and Resilience

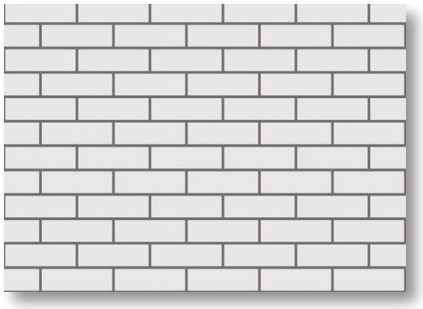
6:42 MIN

TRAINER TIP: ***Optional Video.*** *This may be a good place for a video that illustrates how to enhance strengths and protective factors. You might choose to show a video from the Ralli Campaign. In this6:42 minute video. Harry's experience is a good example of how identifying and enhancing a child's strengths can be a protective factor. Additionally, it provides a good link to the discussion of the "happiness factor," discussed later in the Module.*

- Harry, a student with a speech and language impairment, shares how he felt like an outcast in the classroom and wondered why he was finding things so difficult. The film tells how nurturing of Harry's strengths proved to be as important as supporting his language skills. It also tells about how happy he is now and how positive he is about his future.
- *[Ask participants: what protective factors were strengthened in Harry?]*
- Source: Ralli Campaign, https://www.youtube.com/watch?v=J2eR0Te6wFA

SLIDE 10
Strengthen Family Protective Factors

- Here's a close up of our brick wall from a couple of slides ago. Protective factors can offset many challenges. As providers, your job is to help strengthen protective factors with specific strategies, such as those listed on this slide. We can think of the mortar as what strengthens protective factors. For example, *building* strong social connections, *promoting* family-informed child-centered planning, *helping* families navigate systems of care etc. All of these action-oriented verbs, the "doing" helps strengthen the protective factors.
- These are examples of actions that are the "mortar" to help strengthen family protective factors:
  - **Ask & answer** parents/caregivers' questions
  - **Provide** timely information
  - **Address** traumatic experiences of parents/caregivers
  - **Promote** secure attachment
  - **Promote** a healing & protective environment
  - **Promote** family-informed child-centered planning
  - **Help** families access IDD- & trauma-informed support & services
  - **Partner** with parents to create a recovery team
  - **Help** families navigate systems of care, including systems challenges



- We will now go into each of these actions, the mortar, in more detail.

SLIDE 11
Ask & Answer Questions

5 MIN

- Parents/caregivers have concerns and questions after a child has had a traumatic experience. A provider can start by asking questions. As we discussed in Modules 2 & 3, there is a lot to be found out about the IDD and the traumatic experience(s).
- Additionally, though, providers need information about how the family is doing. What is the family environment like? The dynamics? How much support does the family have?
- And what questions does the family have?
  - Recognize that parents/caregivers questions may center around what's to come. A key role for the provider is to provide anticipatory guidance, especially related to how distress may be diminished and how traumatic experiences may affect the child over time.
  - Ask more questions to figure out where you can be helpful. What are the primary concerns right now (whether or not they seem relevant to you as the interviewer)?

- Some common questions/concerns might be:
  - How to assure safety in the setting in which the trauma occurred?
    - ✓ Is the child still in the setting where the traumatic experience occurred? Does child protective services need to be involved? Does the child need to be in out-of-home care?
  - How to protect the child and still assure as much independence as possible?
  - Will the child ever feel whole and secure again?
    - ✓ How can parents help the child attain a valued and meaningful life, despite the traumatic experience?
  - How to obtain respite or home services?
  - How to maintain developmental progress?

What is the family environment like? The dynamics? How much support does the family have?

- Ask participants to brainstorm about the kinds of questions parents/caregivers may have. *[Allow participants 5 minutes to share ideas at their tables. Ask a few participants to share with the whole group.]*

SLIDE 12
Provide Timely Information

TRAINER TIP: *Nora Baladerian's book, A Risk Reduction Workbook for Parents and Providers, may be useful to highlight as an example of a resource that parents may find helpful to reference for tips on what to talk to children about before, during and after a traumatic event.*

- Efforts to provide early intervention for children with IDD should encompass broad, holistic approaches to support and should complement efforts to provide timely information about trauma.
- Timely information about trauma (which arms parents with information, education, coaching and support) can help parents prepare and anticipate potential dangers, as well as help them know what to do in the face of traumatic experiences and responses.
- Information approaches should have education about specific concepts as a central focus:
  - Optimal relationships between parent(s) and child dyad
  - Addressing emotional needs of the parent(s)
  - Coaching regarding parenting styles which may require alternate techniques required to meet challenging characteristics of the child.
- Education & training needs to be supplemented by in-home modeling and mentoring. This may sometimes provide more concentrated help than a treatment hour with a clinician. However, accessing these types of services may take additional coordination and support from the clinician and child's caregiving system.

SLIDE 13
Address Traumatic Experiences in Parents/Caregivers

- Review the ways in which a parent's personal history of trauma can impact his/her behavior. Parents' own avoidance of trauma reminders can prevent them from seeing "red flags" regarding their own children's safety, or can contribute to minimizing/denying their children's abuse experiences or maximizing/exaggerating their experiences.
  - A parent/caregiver with his/her own trauma history may have experienced first hand how difficult and painful it is to talk about the trauma, and may therefore want to "shield" his/her child from a similar experience.
- Parents whose children have had a traumatic experience often have secondary traumatic stress reactions.
- Past and recent traumatic experiences can impact parents' ability to keep their children safe and to work effectively with providers.
- Coordinating caregivers' care (mental health needs and/or trauma treatment) with child's care (e.g., medical and trauma treatment) can pose challenges.

A parent/caregiver with his/her own trauma history may have experienced first hand how difficult and painful it is to talk about the trauma, and may therefore want to "shield" his/her child from a similar experience.

- When the parent is the source of the traumatic experience of the child, it adds a layer to the dynamics of the caregiver-child relationship, as well as how treatment needs to occur.
  - Safety of the child, in the relationship, must be addressed first.
  - Interventions will vary depending on whether the child is with the parent or out of the home (which often depends on the nature of the trauma etc.). In such cases, specialized therapeutic interventions are typically warranted with the parent, the child, and possibly the dyad, depending on the situation and plan for the family.

SLIDE 14
Promote Secure Attachment

- Optimal child development involves parenting characterized by a relationship that serves as a "secure base" that is protective, nurturing, attuned, and responsive.
  - This relationship provides a source of comfort and a trustworthy haven to which a child can turn when fearful, distressed, or uncomfortable. In a secure attachment relationship, the parent provides comfort and helps the baby/child regulate emotions so that over time the child learns emotion regulation skills. But young children rely heavily on the caregiver to provide comfort.
  - This primary relationship provides a foundation for healthy development that has life-long benefit in resilience in facing life's challenges.

- Recognize the importance of structure, routine and predictability to lowering anxiety.

- As providers, our task is to provide or help parents provide a secure base (secure attachment) as a protective factor or to re-create a secure base when it has been damaged by trauma.
  - Limit-setting can be challenging for parents of children with IDD because they already feel that the child has had to go through so much, but it is necessary in order to provide a secure base.
  - Past parental trauma can alter the parent's ability to be emotionally attuned and sensitive, and may alter the parent's perceptions of safety and danger. If the parent was traumatized along with the child, their current levels of stress/distress can interfere with sensitive, available parenting and they may need additional support themselves to cope with their own distress in order to be a healing resource for the child. Frightening or frightened behavior from the parent is especially worrisome in terms of its effect on the attachment relationship with the child.
- Robust evidence suggests that cumulative exposure to a stable, highly responsive parenting style throughout the early childhood period is associated with a variety of child benefits in diverse developmental strands: language, cognition, emotional stability, and social development. At the same time, there is growing evidence suggesting a possible causal role for *responsiveness* in terms of its impact on those same developmental strands. When studied from an alternate angle, evidence suggests that long-term exposure to a harsh or *unresponsive* parenting style is associated with sub-optimal child outcomes in those same developmental strands.
  - A number of child characteristics associated with developmental delays and disabilities may impact parental responsiveness alone – or in combination with other factors. For example, "unusual" repetitive behaviors, poor eye contact, aggressive outbursts, unintelligible speech or difficulty following directions may be sufficient to affect parent efforts to be responsive.

Optimal child development involves parenting characterized by a relationship that serves as a "secure base" that is protective, nurturing, attuned, and responsive.

  - Similarly, parent characteristics (unrelated to the child's disability) may affect parental responsiveness. With parental depression, for example, responsiveness and resilience of the parent can be compromised, at least temporarily.
  - Traumatic experiences can affect parental responsiveness because they can create more questions and hopelessness/helplessness in the face of a multitude of emotions (e.g., stress, loss, grief, anger).
  - It is important for the parent's responses to the child to be contingent and sensitive (i.e., accurate readings of the child's cues and needs, and empathic, supportive responses). A parent who is very engaged but misreading the child's cues (e.g., being overly intrusive) can be problematic.

SLIDE 15
Promote a Healing & Protective Environment

P 26

- Recognize that helping parents address the current environment of their homes is essential. Many families are stressed by behaviors related to traumatic experiences and responses and IDD. Disentangling and understanding behavior and yet managing it, can be challenging and overwhelming. The slide lists some common principles of effective support for dealing with challenging behavior.
  - As discussed in Module 3, following a traumatic experience, there may be temporary behavioral challenges or ongoing challenges/symptoms that develop into PTSD. Temporary challenges may be able to be addressed by promoting a healing and protective environment, but PTSD may require more specific intervention. We will discuss this further in Module 5.
  - Following a traumatic experience, creating and maintaining consistent routines provide reassurance (e.g., return to normal routines as much as possible, providing additional support/ reassurance if the child has new or worsened fears, limit exposure to media/other traumatic material).
- For children with IDD who have experienced trauma, it is most important for providers and caregivers to create or recreate an interpersonal environment that is sufficiently healing to counteract the trauma. This requires providers and caregivers to imagine a child's experience of trauma and recognize they are coping as best they can. Children need providers and caregivers to use the "micro-behaviors of relationships" attuned to their needs (i.e., common everyday social interactions like facial expressions, physical touch, non-verbal vocalizations like sighs and oohs, and physical postures positioning and proximity). What does it mean to be "attuned"?
  - Recognize a child's emotional state in the moment.
  - Imagine it from the child's perspective.
  - Acknowledge it—reflect it through facial expressions and words (sad, scared, "you might be sad, I would be too…")

  Children need providers and caregivers to use the "micro-behaviors of relationships" attuned to their needs.

  - Gently comfort ("it will change", "together we'll get through it", "it will get better")
- Person-centered tools & interventions can be used to look at creating an environment that makes the behavior expression less challenging to understand and address.
- For young children and children with IDD functioning at an earlier developmental level, relationship-based approaches are most effective.
- There are frameworks (such as Gentle Teaching, Positive Behavior Support & Positive Identity Development) for thinking about challenging behavior that expands behavior management (which can be solely focused on control & compliance) to include a focus on increasing quality of life, changing the environment, increasing alternative means of communication, and sometimes using alternative supports such as pictures. The tools of Gentle Teaching, PBS and Positive Identity Development can be readily learned and used by parents and providers to promote and recreate that secure base.
- We will briefly describe the principles of GT, PBS and Positive Identity Development in the next few slides. There is also more information about GT, PBS and Positive Identity Development in the **Supplemental Materials** section.

SLIDE 16
Gentle Teaching

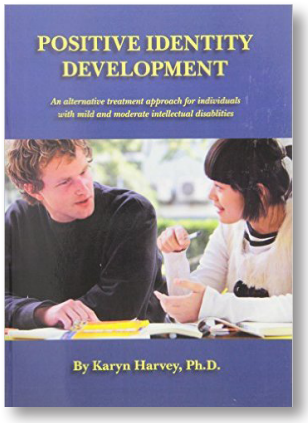
TRAINER TIP: *Make the point that not all behavior management is "bad." Behavior management techniques often also focus on changing the environment as opposed to just being focused on the negative. However, the emphasis of some of the frameworks we are sharing here is on being person-centered and recognizing that behavior occurs within a context.*

- The behaviors that contribute to development of a secure base that serve as a protective factor are the same behaviors that need to be ramped-up in the aftermath of trauma.
- Gentle Teaching is an approach developed in the 1980s by John McGee to interact with people with IDD and challenging behavior. It has since expanded as an effective approach for people with mental illness, older persons, and children and grown an international following.
- Its basic premise is that challenging behavior is a reflection of life experience often characterized by absence of quality of life and/or trauma.
- It focuses on how supporters can interact in ways that improve the quality of life of the person with IDD through meaningful and reciprocal relationships.
- The goal of GT is for the individual to feel safe, loved, loving, and connected.
- Relationships are understood in GT as transacted in repetitive micro-behaviors using the tools of our hands (touch), eyes, voice (words), and presence. These tools and how they can be used are accessible to parents and caregivers as well as providers to communicate:
  - "You're safe with me."
  - "It's good to be with me."
  - "It's good to be loved and be loving."

SLIDE 17
Positive Behavior Support

- Positive behavior support (PBS) is a set of evidence-based strategies used to increase quality of life and decrease problem behavior by making changes in a person's environment and teaching new skills.
- PBS has been effectively used with individuals with IDD and mental health needs.
- PBS applies behavior science in a way that is different from behavior *management*.
- PBS starts with the premise that individuals are coping in the most effective way they know.
- The PBS approach is to change the environment so that individuals can get what they want and teach skills so they have more effective tools to get what they want or cope when they can't.

SLIDE 18
Positive Identity Development



- Positive identity development and levels of happiness have been introduced by Karyn Harvey, PhD as an effective way to promote healing. Understanding levels of happiness, addressed in her book, *Positive Identity Development*, provides markers that can easily be used to help create a safe yet meaningful life.
  - Involves both therapy & a positive behavioral approach
  - Based on the integration of two schools of psychology: positive psychology (Martin Seligman) and existential psychology/Logotherapy (Victor Frankl)
  - Positive identity development for children with IDD focuses on discovering, defining & celebrating the self vs taking on the sole identity of "disabled." Children with IDD not only often see themselves as disabled, but also…
    - ✓ The "bad" kid (due to behaviors).
    - ✓ The dumb kid.
    - ✓ The kid who can't read.
    - ✓ The kid who talks funny.
    - ✓ The kid who can't ride a bike.
    - ✓ The kid who can't drive a car.
    - ✓ The kid who can't!

Positive identity development for children with IDD focuses on discovering, defining and celebrating the self.

- Premise is that an approach modeled on psychological well-being vs ineffective behaviors leads to human health & authentic happiness
  - The Happiness Factor: Dr. Harvey identifies levels of happiness as key to determining behavioral change & adjustment.
  - Oftentimes, children with IDD are given the feedback that they cannot impact their environment in any significant way, which can lead to learned helplessness (i.e., individuals' attempts at controlling their environment are repeatedly thwarted until they become passive & the individuals perceive themselves as helpless).
  - Many children with IDD respond to their sense of helplessness by acting in passive or passive-aggressive ways, and then are labeled as "non-compliant."

SLIDE 19
The Happiness Factor

- In *Authentic Happiness*, Martin Seligman, PhD, outlines 3 levels of happiness:
  - **Pleasure**: things we enjoy in a predominantly happy state (e.g., eating, watching a movie/TV)
    - ✓ Most people need some pleasure in their life, but people who get most of their leisure enjoyment from this passive pleasure level are more prone towards depression.
    - ✓ It's notable that often primary reinforcers/rewards used in behavioral programs are at this level
  - **Engagement**: actually engaging in something pleasurable; requires activity on the part of the participant (e.g., cooking, camping, hiking)
    - ✓ Creates a feeling of total absorption that is more satisfying than passive pleasure
    - ✓ Engagement in pleasurable activities also develops skills & talents
    - ✓ The increase in happiness is related to the development of one's own skills & strengths
  - **Meaning**: the act of making a real difference in the world of others through using one's own strengths, particularly strengths of character
    - ✓ Seligman found that those who experience their lives as having meaning & purpose, & feel that they are contributing in some way to the world around them, have the greatest level of fulfillment & happiness
- Like typically developing children, children with IDD also benefit more from engagement than pleasure, and most from meaning & purpose.
- For more information and resources, visit Martin Seligman's website: http://www.pursuit-of-happiness.org/teaching-resources/
- Specialisterne is an interesting example you may want to highlight here. Specialisterne (which translates from Danish as "The Specialists") is an innovative social business concept originally founded in Denmark in 2004. Specialisterne is internationally recognized as the first and foremost example of how high functioning people with autism (Autism Spectrum Disorder) can become effectively included in society, and provide valuable, high quality services to their employers. Specialisterne works to enable jobs for high functioning people with autism, and similar challenges, through social entrepreneurship, innovative employment models, and a national change in mindset. See http://usa.specialisterne.com/about-specialisterne/ for more information.

SLIDE 20
My Book About Recovery!

- Karyn Harvey, PhD, has developed a number of counseling techniques and forms/workbooks for increasing positive identity development to be completed with clients, which accompany her book, *Positive Identity Development: An Alternative Treatment Approach for Individuals with Mild and Moderate Intellectual Disabilities* (Harvey, 2009).

- Available forms/workbooks:
  - Psychological Needs Survey
  - Happiness Assessment
  - Change Inventory
  - Behavior Planning Template
  - My Book About Myself!
  - My Goodbye Book
  - My Book About Recovery!
  - My Book About Solving My Problem
  - My Book About Making a Difference!
  - My Book About My Relationship
  - My Book About My Addiction
- Materials are available to download and print at http://pid.thenadd.org/.

SLIDE 21
Facilitating Development

- In the last few slides we have described protective factors that may enhance child and family well-being.
- Let's re-visit the developmental tasks that we discussed in Module 2. We know that children are progressing through key developmental tasks during each stage of development.
- This slide identifies ways in which a facilitating environment and facilitating parent messages can help children with these key developmental tasks.

Stage	Task	Facilitating Environment	Facilitating Parental Messages
Infancy	Being	A secure base	*I'm glad you are you.*
Early childhood	Doing	Safe exploration	*You can explore and I will protect you.*
Middle childhood	Mastery	Inclusion with other children	*You can learn the rules that will help you live with others.*
Adolescence	Identity	Opportunity to try on roles	*You can develop your own interests and relationships.*
Adulthood	Separation	Community membership	*My love is always with you.*

- Parental messages are communicated through words but also actions: presence, demeanor, touch, voice and tone.
- Source: Rosenau, N. (2015). Facilitating Development [Chart]. Adapted from Human Development Chart- Erik Erikson's Model of Human Development. Retrieved from http://mcnellie.com/erikson.html.

SLIDE 22
Promote Family-Informed Child-Centered Planning

- Family-informed child-centered planning—provides a process for bringing a child's team of providers together to discuss the child's hopes and dreams. Child-centered planning is a strengths-based process that is a celebration of the child and a mechanism of establishing the commitment of the team members to supporting the child and family. It's about "listening" to the child no matter how he/she communicates and finding out what's important to them.
- In the case of very young children a family-centered approach (i.e., parents are the experts on their child and are active participants and collaborators in the recovery process), has been demonstrated to work best. This is also reflective of a relationship-based approach.
- A plan should integrate requirements and goals across agencies and should not merely be a behavioral management plan.
- This will be discussed in more detail in Module 5.

SLIDE 23
Help Families Access IDD- & Trauma-Informed Support

PP 27-29 P 27 15 MIN

TRAINER TIP: *This is an Activity slide. Have participants fill out the* ***Local Resources*** *handout. Participants should start by identifying 5 local organizations that they frequently refer families to, or find helpful. Once they've created their own list, participants should walk around the room and ask others to share their list–they should come up with 5 new organizations to add to their list. Consider collecting everyone's handout and making copies that could be compiled into one large resource list that would be distributed to everyone after the training.*

- It is important to identify local resources that are trauma-informed. And also important to note that not all IDD supports may be trauma-informed. Asking questions to assess how trauma-informed organizations are is a first step in helping organizations become more trauma-informed. Increasing the demand for trauma-informed organizations often leads to an increase in knowledge- and skill-building among staff.
- **Informal Support** (e.g., community/church groups, extended family, friends, other families with children with IDD)
- **Formal Support**
  - Organizations that provide disability services (e.g., Regional Centers)—note that the names and roles of these organizations vary from State to State. Massfamilyties.org has compiled a comprehensive directory of resources (March 2015) for families of children and youth with special needs.

- Application processes (Individualized Education Plans [IEPs], Supplemental Security Income [SSI], in-home supportive services)—providers can help caregivers access support by being an advocate for the child. Organizations that provide trauma-informed services (e.g., NCTSN has sites in many states across the country). Visit NCTSN.org for a list of NCTSN sites.

- **Families-to-Families Support**
  - Organizations like Family Voices or Parent-to-Parent and other similar family-driven support organizations. Family Voices is an example of a resource for families that provides families-to-families support. Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Throughout a national grassroots network, they provide families resources and support to make informed decisions, advocate for improved public and private policies, build partnerships among families and professionals, and serve as a trusted resource on health care.
  - National Federation of Families for Children's Mental Health & NAMI (National Alliance for the Mentally Ill) are examples of two organizations that provide families-to-families support around mental illness and trauma.
  - See the **Supplemental Materials** section for a list of resources for families.
- **Sibling Support**
  - Sibling Leadership Network is an example of a resource for siblings. Their mission is to provide siblings of individuals with disabilities the information, support, and tools to advocate for their brothers and sisters and to promote the issues important to them and their entire families.
- You should have a handout entitled ***Local Resources***. Think of 5 local organizations who you can regularly use to refer/assist your families with contacting to help them access IDD- and trauma-informed services. Take a minute and write them down on this sheet. Then walk around the room and ask others about the resources they use—keep talking with people until you find 5 new resources to add to your list. *[Allow participants 5-10 minutes to fill this out. Have one or two people share.]*

BREAK

SLIDE 24
Partner with Parents to Create a Recovery Team

- The team of people involved in a child's life can include:
  - Teachers, daycare/early childcare workers, early intervention providers, tutors, and other members of the educational system
  - Parents and other caregivers and family members, such as siblings and extended family (grandparents)
  - Friends & other informal support networks
  - Medical professionals, including pediatrician, developmental specialists (e.g., developmental behavioral pediatrician, neurologist, nurse practitioners)
  - Mental health providers (e.g., psychologist, psychiatrist, social worker)
  - Providers in other child-serving systems (e.g., child welfare, juvenile justice, Regional Centers, federal programs)
  - Respite providers

It is important to make a distinction between a "recovery team" and a "treatment team."

- It is important to make a distinction between a "recovery team" and a "treatment team." In mental health culture, a treatment team might be the team in the clinic responsible for a child's care, consisting of a child's treatment providers. In IDD culture, a team is used more for development a support plan or service plan.
- By "recovery team," we are introducing the idea that children with IDD often have many providers in their life (even prior to a traumatic experience). While we're not suggesting that parents/caregivers must develop a formal "recovery team," it is important for providers to know who are the other professionals involved in the child's care. And also, to find out from parents/caregivers, who they find most supportive and helpful.
- Ideally, every member of the team should be striving for the same goals: a child's safety and well-being, and the development and maintenance of a positive and stable home.
- Each member of the team has distinct roles and responsibilities in the system
  - The connections that are strong, helpful, weak or stressful will vary for different families. Some providers working with the child may have close, positive relationships with a child and family. Others may not be very active or engaged with a child. Still others may be a source of conflict and stress.
  - It is unlikely that all providers that a child with IDD and family encounters will be equally trauma-informed. It is important to know where there are gaps in trauma information so that providers can help parents/caregivers create an effective trauma-informed recovery team.
  - Some members of the team may have trauma histories of their own or they might be experiencing secondary traumatic stress. Secondary traumatic stress refers to the emotional effects of close, constant contact with children who have experienced trauma, and we will talk more about this in Module 6.

SLIDE 25
Help Families Navigate Systems of Care

- Many children with IDD have co-occurring developmental and mental health diagnoses and conditions which results in their involvement with multiple child-serving systems.
- Involvement in multiple systems often means having to deal with obstacles in systems. Sometimes the role of the provider is to help families deal with the frustration and challenge of waitlists and lack of availability of formal supports.
  - Availability
  - Waitlists
  - Tools and ideas to help with uncertainty
  - What we can do while we wait

Sometimes the role of the provider is to help families deal with the frustration and challenge of waitlists and lack of availability of formal supports.

- In the United States, most public and private mental health, rehabilitation, and disability healthcare funding sources are allocated based on categorical diagnoses which may not match children's needs and are segregated into separate financial "silos."
- There are many instances when needed services may be denied by insurance companies or public agencies who "ping-pong" the child back and forth to avoid covering care for children with complex issues. When services are approved, providers with the needed skills (such as trauma-informed treatment or autism-specific treatment) may not be available.
- This can be a resource strain on providers given that successful trauma work with this population requires advocacy and family education.

SLIDE 26
Putting It Into Practice

P 28

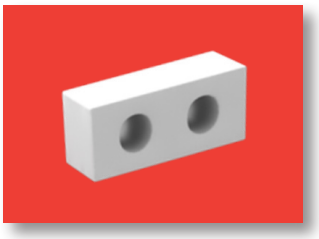

30 MIN

TRAINER TIP: *This is an Activity slide. Have participants pull out Board Game handout. Please see the list of items needed for the game in your Facilitator's Guide and make sure there are enough for each table you have.*

- Right now we are going to play a game at our tables. Pull out the *Board Game* handout you've been given and set up the Board Game at your table.
- We've been talking about ways to support and strengthen child & family well-being and resilience. In this game we are continuing that conversation. The objective is to move your marker from start to finish. Along the way you are going to encounter things that will help strength child and family resilience—or protective factors—as well as situations or circumstances that could hinder or lessen child and family well-being—or risk factors.

- The person who traveled the farthest for the training will go first. Roll the dice and move your marker the number of spaces shown on the dice.
- You could land on one of three spaces:

  1. A blue space where you have to pick up a risk factor card—the cards with the rain on them.
  2. A red space where you have to pick up a protective factor card—the cards with the bricks on them.
  3. Or a yellow space where you do nothing and await your next turn.



- If you land on a space where you have to draw a card, please do so and follow the directions outlined on the back. You don't draw a card on this new space.
- You are going to be moving forward and backward, as well as engaging in dialogue with your table as you move through the game. *[Allow participants 30 – 40 minutes to play the game. Consider giving out prizes to the winners.]*
- Let's come back together even if you aren't finished. So, how was that?
- How did you feel when a protective factor moved you forward a few spaces? *[Allow a couple of people to shout out answers.]*
- What would you say/do to continue this forward movement in a client's recovery? *[Allow a few people to respond.]*
- How did you feel when a risk factor pushed you back a few spaces? *[Allow a few people to shout out answers.]*
- What would you say to support families who experienced the kinds of things that made you move back? How would you offer support to help get them moving forward again? *[Allow a few people to respond].*
- Did you find yourself getting nervous to land on either type of space? Did you ever feel like you just wanted to roll the dice and not have to move forward or backward?
- How would you talk with families who feel stuck where they are in their recovery? *[Allow a few people to respond.]*

SLIDE 27
Essential Messages

- As a recap, let's review the Essential Messages that we just discussed in Module 4.

  6. Utilize an IDD- and trauma-informed child-centered approach to support both the child and the family.
  7. Help parents/caregivers, and other professionals in the child's life, strengthen protective factors.

SLIDE 28
What Can a Provider Do?

P 29


5 MIN

TRAINER TIP: *This is an Activity slide, which will recur at the end of each Module. This is the opportunity for participants to reflect on their own practice and think concretely about what they can enhance or do differently, based on the information that was just presented to them in Module 4. Participants will be given a checklist to fill out to help guide their reflections. Emphasize to participants that if they feel that the options are too clinically focused, they should create strategies that are relevant to their role.*

- Here are some things that you as a provider can do to address the concepts that we discussed in Module 4. Think about the child you identified at the end of Module 1 who connects you to this work. What can help that child and other children with IDD who have experienced trauma? Let's take a few minutes to think about what you can do specifically in your role and at your organization to address any one of these points.
- Pull out your handout titled, ***Action Planning: Essential Messages 6 & 7***. This is your opportunity to think about how you are going to implement the ideas that we just discussed in Module 4, into your daily practice, as soon as you get back to your office. You will see that the handout outlines specific strategies for things that you can do to address the Essential Messages. These strategies were written in SMART objective format (Specific, Measurable, Achievable, Results-Oriented, Timely). Mark an "X" in up to three boxes next to the ideas that you think you would MOST like to emphasize in your daily practice for the Essential Messages. If you would like to create your own strategy, using SMART objective format, you are welcome to do that as well. *[Allow 5 minutes to complete the activity. After activity is done ask 2-3 people to share one strategy they think they would like to implement starting tomorrow.]*

Facilitator Notes
Module 5: IDD- & Trauma-Informed Services & Treatment

SLIDE 29
Module 5: IDD- & Trauma-Informed Services & Treatment

- In the last Module we discussed the role of protective factors, such as a secure attachment and a healing/protective environment, in enhancing child & family well-being & resilience, and how to provide practical tools and support for parents/caregivers.
- In this Module, you'll learn how to enhance protective factors of children with IDD and families through IDD and trauma-informed trauma assessment & screening and referral to appropriate trauma-informed services & treatment.

SLIDE 30
Module 5: Learning Objectives
What Will I Learn Today?

After completing today's training, you should be able to do the following:

1. Explain how to enhance protective factors of children with IDD & families through appropriate trauma-informed services & treatment.
2. Discuss how to utilize adapted screening, assessment and planning tools to identify IDD- and trauma-informed needs of children and families.
3. Discuss strategies for adapting the core components of trauma-informed treatments for children with IDD.
4. Identify strategies for partnering with agencies & cross-system collaboration.

SLIDE 31
Multiple Providers, Multiple Hats

- It's important for providers to know the full range of services (both IDD and trauma) that a child with IDD may need so that he/she can make appropriate referrals when necessary and help families navigate multiple systems at various points along the way.

- Sometimes one provider has multiple roles; most of the time, multiple providers each wear multiple hats.
- This often means that providers have to be flexible in thinking about their own role. Many providers feel like they are not trained in case management and coordination but children with IDD and their families frequently need other supports in addition to traditional therapy.
- The nature of healthcare systems results in authorization denials that require advocacy and complicated appeals. This means that providers have to become advocates and insurance experts to help get their clients the best possible services.
- The presence of "silos" (i.e., IDD, trauma, mental health treatment may each be provided by different agencies) also contributes to multiple providers.
- *[Ask participants]*—What are some other roles that providers might have?

SLIDE 32
Potential Pathways for Identifying IDD & Trauma

- The diagnostic complexity of IDD and trauma often results in multiple caregivers and multiple hats for providers.
- The complexity is due, at least in part, to the type and timing of the traumatic experience, as well as how much is known about the trauma.
  - Known trauma
  - Suspected trauma
  - Unsuspected trauma/unidentified trauma, which may present as a behavioral challenge.

An interdisciplinary model optimizes referral of the child with IDD who is presenting with symptoms of trauma.

- A strategy is needed to address this diagnostic complexity, which is interdisciplinary in nature.
- An interdisciplinary model optimizes referral of the child with IDD who is presenting with symptoms of trauma. Below is outlined a clinical flow with decision elements:
- **Natural/Informal family supports**. Families notice that development is not occurring as they expect and they reach out to formal and informal supports for information and resources.
- **Primary Care Provider** (General Pediatricians, Family Practitioners, Advanced Nurse Practitioners and Physician Assistants)/**Educators** for initial history and physical examination, preliminary screening. The Primary Care Provider/Educator will decide whether involvement of Child Protective Services and Law Enforcement Agencies is indicated.
  - Primary care providers hold a unique position in often being the first and frequent point of contact with the health care system for children with IDD. These providers offer well child care along with typically seeing the child soon after caregivers have a particular concern. For example, if there is an injury or new behavioral symptom, primary care includes performing an initial physical examination and laboratory tests, or utilization of developmental and behavioral screening tools, to clarify the etiology and begin treatment/interventions. This process of preliminary investigation may elucidate findings that suggest abuse or trauma and the primary care provider responds by initiating referrals to protective services, subspecialists and mental health providers, depending on the indications.

- **Other Pathways** (e.g., Regional Center/Schools).
  - ✓ Regional centers are nonprofit/State-run organizations that contract with the Department of Developmental Services (varies by State) to provide or coordinate services and supports for individuals with DD. They may have offices throughout the State to provide a local resource to help find and access the many services available to individuals and their families. However, the challenge is that each State has a different system for providing services and even within States, there may be variability in terms of quality and accessibility of services.
  - ✓ Neuropsychological/psychoeducational assessment. Might occur through an IEP process at school. Variable in terms of the length of time and quality of the assessment. Private assessments can be quite costly. Insurance coverage for this type of evaluation varies by company and plan. This leaves many families with few options in order to provide the best evaluation for their child.

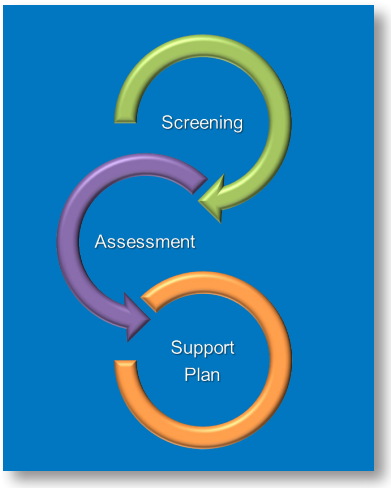
- **Referral to Early Intervention Provider/Child Abuse and Neglect Pediatrician/Child Advocacy** resources if more extensive forensic interview and examination is needed (unclear mechanism of injury, vague reports from child or caregivers).
  - Clarification of adaptive functioning and behavior
  - Assessment of social-emotional functioning
  - Identify primary developmental behavioral condition
- **Referral to Developmental-Behavioral Pediatrician** to clarify child's adaptive functioning and behaviors and social-emotional functioning; these may be unexpected for child's chronological age but congruent with developmental level. The Developmental-Behavioral Pediatrician's role is to provide focused behavioral observations and standardized assessments to identify the child's developmental functioning across multiple domains—cognitive, social-emotional, behavioral, academic (when applicable), and fine and gross motor skills. This may help distinguish the child's primary developmental-behavioral condition from symptoms that are responses to traumatic experiences.
- **Referral to Trauma-Focused Therapy** that is appropriate/adapted to child's intellectual level (Psychology, Social Work, involvement of Occupational Therapy and Physical Therapy as needed to help child participate in therapy).
- **Referral to Parent Support/Parenting Classes** to help parents/caregivers cope with and constructively address challenging or disruptive behaviors related to traumatic experiences (panic attacks, frequent masturbation, self- injury, lack of socialization).

SLIDE 33
Identify IDD-Related Support Needs of Children & Families

P 30

- How do families and providers learn about a child's disability? What it is the screening and assessment process? How do they figure out how it is impacting their life / world?
- Identifying IDD-related support needs of children & families is essential to determining the kinds of accommodations that are necessary, as well as areas for skills development.
- **Developmental surveillance** is an important technique used by pediatricians which includes components such as eliciting and attending to parental concerns, obtaining a relevant developmental

history, making accurate and informative observations of children, and sharing opinions and concerns with other relevant professionals. It is defined as "a flexible, continuous process whereby knowledgeable professionals perform skilled observations of children during the provision of health care" (Dworkin, 1993). For further information, see recommendations developed by AAP (2001, 2006, 2014) in *Developmental Surveillance & Screening of Infants and Young Children*, in the **Supplemental Materials** section.



- **Screening** is a "brief assessment procedure designed to identify children who should receive more intensive diagnosis or assessment" (Meisels & Provence, 1989). Developmental screening is aimed at identifying children who may need more comprehensive assessment.
- The role of the provider when meeting with a family and child with IDD is to understand how the child is functioning. There are standardized screening and assessment tools for this, but information from parents is invaluable in this process as they are often making comparisons between their child and his/her peers constantly. They have a wealth of knowledge about how the child is functioning and a good sense of their developmental stage and how that may compare to expectations given the child's chronological age.
- There's a difference between families who learn about an IDD diagnosis early (e.g., in utero congenital disability, Down's syndrome) vs. later in the child's life. If a diagnosis is made in utero, **anticipatory guidance** can occur right away to help prepare the family to adapt to a different pace and pinnacle of development. Families who learn about a disability due to a later diagnosis or because developmental milestones weren't met, have a different set of challenges involved in adjusting expectations. Even when an IDD diagnosis is made in utero (e.g., Down syndrome), the family/provider won't know what level of abilities the child has until later on. There is a lot of variability, again impacted by risk & protective factors.
- Federal & national initiatives emphasize screening & early identification of delays
  - AAP Guidelines for Screening
  - Birth to 5: Watch Me Thrive, ACF Initiative
  - IDEA Amendments

SLIDE 34
Ages & Stages Questionnaires (ASQ-3)

TRAINER TIP: *One of the challenges that providers often encounter when trying to use screening & assessment tools is that they have to be purchased. There are a few instruments, such as the Modified Checklist for Autism in Toddlers, Revised (M-CHAT-R) and the Strengths and Difficulties Questionnaire (SDQ) that are free to use and may be helpful as a starting point in obtaining information from parents/caregivers.*

- **Ages & Stages Questionnaires, Third Edition (ASQ-3)** is a developmental screening tool (covers communication, fine & gross motor skills, problem-solving, personal-social) designed for use by early educators and health care professionals. It relies on parents as experts, is easy-to-use, family-friendly and creates the snapshot needed to catch delays *and* celebrate milestones.
- There is also the **Ages & Stages Questionnaire: Social-Emotional Second Edition (ASQ:SE-2)**, which focuses on social and emotional development in young children.
- Available for purchase at: http://agesandstages.com/products-services/asq3/

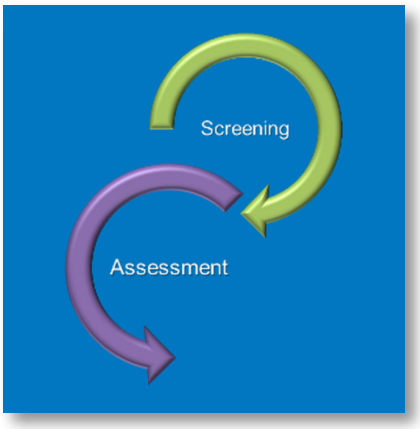
SLIDE 35
PEDS Response Form

- **Parents' Evaluation of Developmental Status (PEDS)**—A surveillance and screening tool, for children 0 to 8 years, that elicits and addresses, with evidence-based support, parents' concerns about development, behavior and mental health. PEDS saves time, promotes family collaboration and willingness to return for future visits. It is published in many languages and includes abundant information to support helping parents learn about child-rearing.
- **PEDS: Developmental Milestones (PEDS:DM)**—a surveillance and screening tool for children 0 – 8 that enables a swift view of children's skills in development and mental health, including expressive and receptive language, fine and gross motor skills, self-help, academics, and social-emotional skills. The PEDS:DM also includes supplemental measures of psychosocial risk, resilience, autism-specific screening (M-CHAT), and several screens for older children including the Vanderbilt ADHD Scale. An Assessment Level version is also available to help with early intervention intake and NICU follow-up.
- Available for purchase at PEDStest.com.

SLIDE 36
Developmental Assessment

- Assessment may lead to a definitive diagnosis, development of an interdisciplinary comprehensive plan of remediation, realization that there is no significant problem, or a decision that additional observation is warranted.
- An IDD diagnosis can occur in many different child-serving systems, from the pediatrician's office during a well child visit to schools, Regional Centers, SSI.
- Additionally, different states have different regulations and eligibility criteria. Some systems may only accept an assessment that occurs within their system.
- The result is that children with IDD and families may have to go through many different "doorways" to try to find appropriate services.
- Assessment may occur informally (e.g., observation, clinical interview, parent interview) or formally (use of assessment tools) across settings.

SLIDE 37
Challenges in the Screening & Assessment Process



- We've just outlined the screening & assessment process. However, we know that early identification, diagnosis and service planning of children with IDD is quite challenging.
  - Delivery of primary care to children with IDD presents distinct difficulties to the providers. Even basic **communication** with these children may be a struggle because they may be nonverbal and/or use assistive communication devices, such as picture systems or computer programs/tablets that the provider may be unfamiliar with. Depending on the child's specific cognitive level and home and school resources (therapies, assistive devices) he/she may have more or less facility with communication.
  - Some children with IDD also have complex and chronic **medical comorbidities** such as chronic lung disease, seizures, and complex feeding problems that may require reliance on technologies, such as tracheostomies, home oxygen, and gastrostomy tubes.
  - These multiple health-related needs require intensive **coordination of services** and therapies and often prove time consuming, detracting from a focus on screening for trauma and related behavioral conditions.
- The American Academy of Pediatrics (AAP) Committee on Children with Disabilities (2001) outlined challenges to the screening & assessment process:
  - Delays in accurate diagnosis & appropriate intervention
  - Delay in skill becomes evident only at age when specific developmental milestone is expected
  - Early recognition of delays requires in-depth knowledge of precursors to skill as well as clinical judgment
  - Mild delays & deviations are often hard to detect because children develop in spurts & sometimes discontinuously
  - Developmental disabilities encompass a spectrum of problems of varying kinds & severity
  - Not complete consensus among professionals or between parents & physicians as to severity at which evaluation & intervention become appropriate.
  - Referral for assessment may provoke anxiety in parents, thus providers may tend to identify only markedly delayed children
  - Child development is a dynamic process
  - Developmental screening tests have inherent limitations & are controversial, limited ability to predict future functioning

SLIDE 38
IDD- & Trauma-Informed Services & Treatment

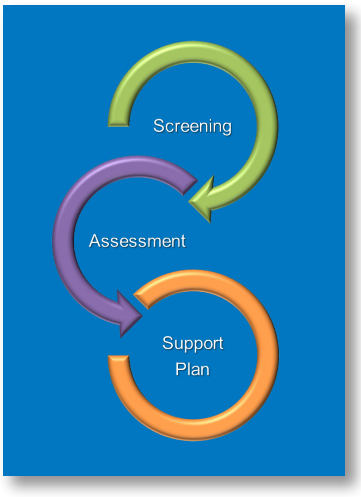
- As we stated earlier, there are multiple providers involved in a family and child's life, and even more providers if that child has IDD and/or has had a traumatic experience. These providers have many roles in the process of helping the family obtain IDD- & trauma-informed services and treatment.

Providers have many roles in the process of helping the family obtain IDD- & trauma-informed services and treatment.

  - **Trauma-informed services** refers to a broad array of support and care, including treatment.
  - **Trauma-informed treatment** refers to interventions that focus on addressing symptoms and responses to traumatic experiences.
- We will discuss both services and treatment in greater detail in this Module.

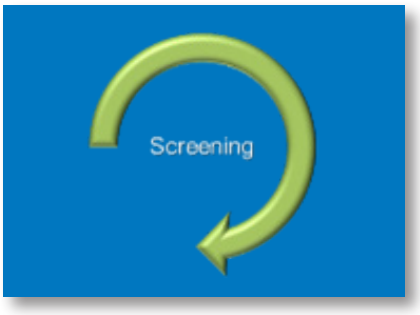
SLIDE 39
Identify Trauma Informed Services & Treatment Needs of Children and Families

- In Module 3 we talked about the impact of traumatic experiences and responses. Now we need to discuss how to identify the individual trauma-related needs of children with IDD and their families. A first step is screening and assessment.
- There are different paths that may lead to trauma-informed treatment. Sometimes the trauma that a child experienced is known. Other times, a child may present with behavior changes or challenges without recognition of trauma history or contribution.
- Systematic trauma screening and assessment can be helpful, especially when the trauma history is unknown.
  - Given the known risk for trauma exposure for children with IDD (as we discussed in Module 1), a brief trauma screen is recommended when children with IDD and families present with problems.



- Providers should consistently use a screening tool to identify a child's trauma history and traumatic stress responses (e.g., including sleeping, eating, coping) and to direct referrals for treatment.
- Providers should share the results of the trauma screening with the team, as appropriate (it is important to maintain confidentiality). The worker and team should develop a plan regarding how the results of the screening will guide decision making and planning for safety and well-being.
- Agencies & organizations can also collect information about trauma and its impact on families served, and use this aggregate information to develop policies, supports, and other resources.

SLIDE 40
Trauma Screening



- **Trauma Screening** often may be administered by a front-line worker (e.g., service coordinator, case worker) to determine a child's trauma history and related symptoms.
- Screening for abuse and traumatic stress often includes an interview with the primary caregiver, child and family. A family centered approach allows identification of cultural, socioeconomic, and religious factors defining the family's values and problem-solving strategies. The communication limitations of the child may hinder use of standardized screening instruments and interview techniques.
- Standardized trauma screening tools may need to be adapted for children with IDD. For example, communication limitations of the child may hinder use of standardized instruments and require adaptations.
- Standardized trauma screens and assessments may have already limitations when we think about very young children and therefore need to be adapted. Unfortunately, there is a scarcity of developmentally appropriate trauma instruments for very young children.
- *[Ask participants how trauma screening may need to be adapted for children with IDD.]*
- Visit the NCTSN Measures Review Database (MRDB) at http://www.nctsn.org/resources/online-research/measures-review for information on trauma screening tools.

SLIDE 41
Trauma Screening for Parents/Caregivers

- Caregivers and families of children with IDD are themselves at risk for trauma and mental health problems and their conditions may impact their engagement in screening and reliability.
- Trauma can interfere with their ability to protect and support their children
- When screening parents for traumatic experiences, it may also be appropriate to ask about other members of the family (e.g., other children/siblings).
- Examples of screening tools for parents:
  - Parent Emotional Reaction Questionnaire: assesses stressful parental emotional reactions to the sexual abuse of their children
  - Life Events Checklist
  - Trauma Recovery Scale
- Visit the NCTSN Measures Review Database (MRDB) at http://www.nctsn.org/resources/online-research/measures-review for information on trauma screening tools for parents/caregivers.

SLIDES 42-43
Trauma Assessment

- **Trauma Assessment** is used if a child has a history of trauma and is currently displaying trauma symptoms. The assessment identifies the child's and family's emotional and behavioral reactions to the trauma. Assessment results drive treatment planning and help determine whether the child and/or family might benefit from a trauma-specific treatment approach. The assessment is completed by a mental health provider, often using standardized assessment measures as well as clinical interviews and observation.
- It is important to include parents/caregivers in the assessment process. This is a good time to let parents/caregivers know what the process is (i.e., how assessment helps drive treatment planning) and how (and at what point) families should be involved.
- If a child screens positive for trauma exposure and trauma-related symptoms, referral to a specially trained mental health provider for a thorough trauma assessment is indicated.
- The mental health provider then uses the assessment results to determine the best course of treatment, based on the child's and family's identified needs.
- Trauma assessment is comprehensive and covers multiple domains.
- Assessment may use standardized clinical measures to assist in identifying the types and severity of symptoms the child is experiencing.
- An effective assessment will engage parents and caregivers and incorporate their input.
- *[Ask participants why trauma assessment is important, and draw on the following points:]*
  - Assessment provides a structured framework to identify the clinical needs of the child.
  - Assessment helps to clarify what kind of treatment is most appropriate for the child and the family (e.g., trauma-informed treatment or other kinds of treatment).
  - Assessments may need to be adapted for children with IDD. *[Ask participants how trauma assessments may need to be adapted for children with IDD.]* We will discuss this more in a few moments.
- Assessment and re-assessment is an ongoing process and part of treatment.
- Visit the NCTSN Measures Review Database (MRDB) at http://www.nctsn.org/resources/online-research/measures-review for information on trauma assessment tools.

SLIDE 44
UCLA PTSD Reaction Index

- **The UCLA PTSD Reaction Index for DSM-V** is a self-report questionnaire to screen for exposure to traumatic events and assess PTSD symptoms in school-age children and adolescents. The scale assesses the frequency of occurrence of PTSD symptoms during the past month (rated from 0 = none of the time to 4 = most of the time). The items map directly onto DSM V criteria.
- Available for limited use or for purchase through UCLA. Contact hfinley@mednet.ucla.edu.

SLIDE 45
Trauma Symptom Checklist for Children (TSCC)

- **The Trauma Symptom Checklist for Children (TSCC)** evaluates posttraumatic symptomatology in children and adolescents (ages 8 to 16, with normative adjustments for 17 year-olds), including the effects of child abuse (sexual, physical, and psychological) and neglect, other interpersonal violence, witnessing trauma to others, major accidents, and disasters. The scale measures not only posttraumatic stress, but also other symptom clusters found in some traumatized children.
- Available for purchase through PAR, Inc.: http://www4.parinc.com/Products/Product.aspx?ProductID=TSCC

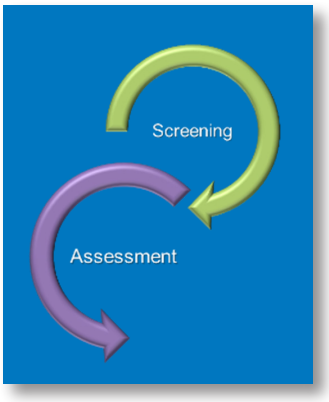
SLIDE 46
NCTSN Measures Review Database

- Searchable database of reviews of tools that measure children's experiences of trauma, their reactions to it, and other mental health and trauma-related issues. Measures can be identified by title, author, acronym or trauma type.
- Source: http://www.nctsn.org/resources/online-research/measures-review

SLIDE 47
Trauma Screening & Assessment: Adaptations for Children with IDD

- IDD may impact child's ability to communicate trauma history verbally.
- When the child's ability to communicate is impaired, it is important that a wide range of caregivers be considered, *in addition to the family*, as possible supports through the assessment and treatment process. These could include parents/guardians and school or daycare personnel with whom the child feels comfortable and who can communicate well with the child.

- It is important that caregivers receive training on the type of behavioral changes (e.g., hypervigilance, avoidance) that may be associated with trauma exposure so they may recognize symptoms in young children or older children with disabilities.
- Many children with IDD have communication limitations. In such cases, it is extremely important to slow down speech, use simple language, present one concept at a time and integrate the use of visual testing materials as much as possible (e.g., photographs, drawings etc.).
- It will also be important to attend to nonverbal forms of communication with children with IDD. For example, if a child raises their voice, becomes more fidgety, or seems increasingly anxious when asked certain questions, this may be a better indicator of a trauma response than whether they endorse specific symptoms.



- It is important to do a careful assessment of functioning continuously, in conjunction with assessing symptoms related to the traumatic experience.

LUNCH

SLIDE 48
Developing IDD- & Trauma-Informed Recovery Plans

P 30 | 30 MIN | PP 31-32

TRAINER TIP: *This is an Activity slide. Participants can use the* ***Putting It Into Practice: Fish Bowl*** *handout for reference. Participants will work together in groups of 4. Allow 20-30 minutes for this activity. Consider modifying this exercise to make it more relevant, if the training group is primarily non-clinical.*

- The key to developing effective IDD- & trauma-informed recovery plans is to merge best practice from IDD-informed care (e.g., person-centered planning) with best practices in trauma-informed care (e.g., evidence-based trauma treatments).
- The goals of person-centered planning are to help the child meet desired life outcomes/goals, have positive identity development, and be happy.
- Person-centered practices are tools for meeting these goals.
- A number of person-centered planning tools have been used successfully in supporting individuals with disabilities including PATH, Essential Lifestyle Planning, MAPS, and Personal Futures Planning. While they use different terms, they share common features.

- A family-centered approach includes the family/caregivers as active partners in the treatment and recovery of the young child. An Individual Family Service Plan (IFSP) is a planning and intervention tool used in early intervention. See the **Supplemental Materials** section for more information about person-centered planning and sample plans (http://www.learningcommunity.us/sample_plans.htm).
- Let's put this into practice. Split up into groups of 4. Once you have your groups, please take your chairs and put them in a cross formation so a pair of them is facing one another and the other pair is facing on another. It will look like a +.
  - At your tables, assign a pair of chairs facing each other to be a provider and a family member, and the other pair to be two observers.
  - Now take a seat and either choose a case vignette from your ***Participant Manual*** or think of a child/parent on your caseload to role play.
  - Once the activity starts the provider will begin asking the family member questions to start the process of getting this family closer to a IDD- & trauma-informed recovery plan. Think of everything we've already talked about. Do you want to get information on the IDD diagnosis, or maybe the traumatic experience? Do you bring up screening and assessment? Identify risk or protective factors?
  - While the role play is occurring the two observers will watch and listen. At any point during the role play, the observers have the opportunity to pause the role play and give the provider helpful, supportive, or constructive feedback. When the feedback is done the role play can continue.
  - When I say stop, everyone will freeze, each group will stand and rotate clockwise, changing the roles of each group member. When I say continue, the group will carry on where the last one left off. Observers will then be able to pause the game as seen fit.
  - This will go on until everyone has a chance to be the provider, family member, and the observer.
  - Once everyone has gone through all 3 roles, we will have a large group report out to talk about how that felt, what worked well, what you would chance next time you are confronted with the same situation, etc.

SLIDE 49
Examples of Trauma-Informed Evidence-Based Treatments

PP 33-36

- This slide lists some examples of evidence-based treatments that are used with children and families who have experienced trauma. The handout in the **Supplemental Materials** section, *Empirically Supported Trauma-Informed Treatments and Promising Practices* includes a more extensive list of treatment options.
- Some other promising practices include:
  - Child and Family Traumatic Stress Intervention (CFTSI)
  - Cognitive Behavioral intervention for Trauma in Schools (CBITS)
  - Real Life Heroes
  - Sanctuary Model
  - Seeking Safety for Adolescents

- The NCTSN website (http://www.nctsn.org/resources/topics/treatments-that-work/promising-practices) includes fact sheets on many of these evidence-based treatments and promising practices. *[Ask participants if they have worked with therapists who provide any of these treatments and, if so, to share their experiences. Are they using them with children with IDD?]*
- It is helpful for participants to hear about if these treatments are being used with children with IDD and to know which community providers are trained to provide trauma treatment.

SLIDE 50 (OPTIONAL)
Components of Trauma-Focused Treatment

6 MIN

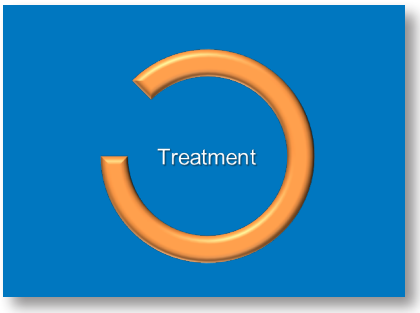
TRAINER TIP: *Optional Videos.* *This may be a good place for a video on the components of trauma-focused treatment. You might choose to show a video clip from The Promise of Trauma-Focused Therapy for Child Sexual Abuse: Dealing with Child Sexual Abuse. If you are using the full version of the video, begin at 18:34. The clip describes the components of Trauma-Focused Cognitive Behavioral Therapy (TF-CBT), which can be applied to other trauma-informed treatments, as well. Another option is to use a clip from Adapting Trauma-Focused Cognitive-Behavioral Therapy. In that video, Brian Tallant, MS, NCC, LPC gives a presentation on how to adapt TF-CBT for individuals with disabilities.*

- *The Promise* video was developed to provide information about the impact of child sexual abuse, to emphasize the importance of including parents/caretakers in treatment, and to highlight the need for children in therapy to learn specific skills to deal with what has happened to them and to talk about the details of their sexually abusive experiences.
  - Available for purchase at: http://www.nctsnet.org/trauma-types/sexual-abuse#q6 or to stream at: https://vimeo.com/44524868.
  - It is also available on the Trauma & IDD Toolkit site of the NCTSN Learning Center: http://learn.nctsn.org/course/view.php?id=370.
- In the *Adapting Trauma-Focused Cognitive-Behavioral Therapy* video, Brian Tallant, MS, NCC, LPC gives a presentation on how to adapt TF-CBT for individuals with disabilities.
  - Available for purchase at http://ddd.uwo.ca/resources/BreakingThe%20BarriersDVDOrderForm.pdf.

SLIDE 51
How do trauma treatments work?

- There is no "one size fits all" when it comes to treatments for children who have experienced trauma. However, research has shown that most effective trauma-informed treatments include some common elements.

- First, they are based on scientific evidence rather than just someone's idea about what works. This means that these treatments have been systematically studied, and data demonstrating their effectiveness have been published.
- They include a comprehensive trauma assessment to determine the child's trauma history and needs.
- After the assessment, the provider proposes a treatment plan, which includes involvement of parents, family, or guardians in the child's therapy.



- Trauma-informed therapy actively addresses the child's traumatic experiences and traumatic stress symptoms. This type of treatment has been proven effective for children of every age, from infants and toddlers to teenagers. It is never "too late" for a child (or an adult) to seek treatment for trauma-related responses.
- For young children, relationally-based interventions seem to work best as young children spend so much time with their caregivers. The relationship has sustainability after the intervention has ended.
- Sometimes there may be a lack of caregivers who can provide an accurate history of trauma experienced by the child (e.g., children in foster care) and/or records or documentation may not be available. In such cases, providers may have to rely on the child's perception of what happened, and/or their ability to communicate about it.
- Many effective trauma treatments rely on cognitive behavioral strategies to help children challenge thoughts that are not serving their recovery.
- These strategies allow children to express their emotions and feelings about the traumatic experience in a way that feels safe for them.
- Several studies have shown the effectiveness of treatments for traumatic stress that are based on what psychologists call cognitive-behavioral approaches. These approaches include:
  - Teaching children **stress management and relaxation** skills to help them cope with unpleasant feelings and physical sensations about the trauma.
  - Using what therapists call "**exposure strategies**," or talking about the traumatic event and feelings about it at a speed that doesn't distress the child.

There is no "one size fits all" when it comes to treatments for children who have experienced trauma.

  - Creating a coherent "**narrative**" or story of what happened. It is often a difficult process for children to reach the point where they are able to tell the story of a traumatic event, but when they are ready, the recounting enables them to master painful feelings about the event and to resolve the impact the event has on their life.
  - **Exploring potentially untrue ideas** about what happened and why. Children sometimes think something they did or didn't do may have caused the trauma, or that if only they had acted a certain way a traumatic experience might have turned out differently. This is rarely true, and getting the story right helps a child stop prolonging the traumatic stress by punishing him- or herself.
  - **Changing unhealthy and incorrect views** that have resulted from the trauma. Children often need help to overcome such ideas as "if he did that bad thing to me it must be because I'm bad" or "children like me can never have a normal life again."

- **Involving parents**. Parents can play an important role in treatment, sometimes by participating in interventions with the therapist and by helping the child practice new therapeutic strategies at home. Parents have key information about their child that therapists need in developing and implementing treatment. Most importantly, parents can create the stable, consistent and caring environment in which the child can learn that a traumatic experience doesn't have to dominate life.

- We now know that there are clinically sound treatments for trauma that are indeed helpful for children and adolescents. There are also relationship-based treatments for very young children (infants and young toddlers), like infant/Child-Parent Psychotherapy, that have evidence of effectiveness for treating trauma, and can be useful for children who are too young for cognitive-behavioral therapy.

SLIDE 52
Narrative Adaptations for Children with IDD

- Brian Tallant, MS, LPC has made adaptations to TF-CBT for children and adults with IDD. He suggests that TF-CBT is a good model to adapt because:
  - It is a strength based approach
  - It focuses on development of competency skills
  - It uses cognitive behavioral treatment techniques which are relatively easy to adapt for people at different developmental levels
  - It has already been structured for use across a wide range of developmental levels
  - It focuses on developing skills that are associated with greater resilience
    - ✓ Strong self-esteem
    - ✓ Ability to self-sooth
    - ✓ Feelings of competency to deal with challenging situations
- Ideas for adapting psychotherapy for children with IDD
  - Slow down your speech
  - Use language that is comprehensible to the client
  - Present information one item at a time
  - Take frequent pauses during the session to check comprehension
  - Use multisensory input
  - Make specific suggestions for change
  - Allow time to practice new skills
  - Do not assume that information will generalize to new situations
  - Include multiple caregivers in various environments
- This slide is an example of some of the specific adaptations he suggests for the trauma narrative component of TF-CBT.

SLIDE 53
Trauma Services & Treatment Adaptations for Children with IDD

- IDD may impact a child's ability to communicate trauma history verbally.
- Many treatments rely on cognitive skills (e.g., trauma narrative). Providers should **identify the "cognitive floor"** for use of a particular therapy & use nonverbal/multisensory tools when necessary.
- Remember that **change may occur more slowly** with some children than with others. Measure change with a micrometer rather than a yardstick.
- Remember that effective treatment for people with developmental disabilities must also include a variety of **support and education services for families** and caregivers.
- It is important for providers to be thoughtful about how to modify intervention strategies for children with IDD, particularly evidence-based interventions which have specified treatment protocols in place.
  - For example, if an intervention is focusing on identifying trauma reminders, the task for the provider may be to come up with alternative strategies for a child who has limited verbal abilities to address reminders (e.g., teach the child to take your hand when experiencing a reminder vs. relying on verbal communication of that reminder). *[Ask participants for ideas about additional adaptations to trauma services and treatment that should be considered for children with IDD.]*

SLIDE 54
IDD- & Trauma-Informed Services & Treatment: Questions to Ask

- You may be a trauma-informed therapist, or you may be another provider of services making a referral.
- This slide lists questions to ask therapists or agencies that provide services to determine whether they are trauma-informed. Workers may feel uncomfortable asking these questions of mental health providers, but children who have been impacted by trauma need and deserve a specialist, just as children with serious dental problems need an orthodontist.

SLIDE 55
Other Services That Enhance Resilience & Recovery

- It is important to point out that not all children exposed to trauma need trauma-informed treatment. Some children benefit from sports or participation in a mentoring program. These other services can also be used in conjunction with trauma treatment.

SLIDE 56
Trauma & IDD: Create an Integrated System of Care

TRAINER TIP: *There is animation on this slide but it is timed, so you don't have to do anything to initiate it. Names of systems will pop up randomly.*

- Due to overlapping disabilities, quality trauma treatment involves integrated care between families, mental health providers, primary care providers, medical specialists, special educators, advocates, and developmental disability services. It is critical to involve caregivers in all environments and intensive care coordination improves outcomes of treatment.
- In contrast to a fragmented approach, cross-system coordination views the child and family in a holistic manner. When different systems have many different and potentially competing priorities, there is a risk that children and their families will receive mixed or confusing messages—or simply fall through the cracks.
- Conversely, these multiple agencies and individuals also have the power, individually or in combination, to actually inflict secondary stress upon the child. For example, in some communities, when sexual abuse occurs, the child might be re-traumatized by having to tell about the details of the abuse on multiple occasions to five or six different interviewers representing various agencies. Though designed to protect children from further abuse, these interventions can be immensely stressful for children.

In contrast to a fragmented approach, cross-system coordination views the child and family in a holistic manner.

- Children with IDD and their families often have legal issues (denial of benefits, special education, child welfare/juvenile justice involvement). Attorneys and judges could use some guidance on trauma & IDD.

SLIDE 57
Strategies for Cross-System Collaboration

PP 37-45

TRAINER TIP: *Ask participants which of the strategies listed on the slide they have tried, and whether they were effective. You may choose a few strategies to highlight, and give examples of successful collaboration.*

- Be cautious that involving multiple providers and collaborating across systems doesn't result in a diffusion of responsibility to the point that no one is responsible for the child anymore.
- See the **Supplemental Materials** section for a checklist of effective strategies, developed by Georgetown University (2014), to be used by administrators, program directors and clinicians.

SLIDE 58
Remember These Faces?

PP 13-18 & 31-32 | 20 MIN

TRAINER TIP: *This is an Activity slide. Refer to 2 handouts,* ***Putting It Into Practice—Case Vignettes: Accessing Services*** *and* ***Protective Factors****, for this activity. It is designed to pull together all the information presented in Modules 4 & 5. Participants will work together at their tables to fill in the information requested. Walk around and assign one of the cases to each group. Make sure that each case is represented at least once. The participants will identify the protective factors for the child and family they have been assigned, anticipate challenges & barriers they may encounter with that family, and in what ways—keeping screening and assessment in mind—that they can advocate for the families. Participants can refer to the* ***Protective Factors*** *handout to refresh their memory. Allow 20 minutes for this exercise. Consult Appendix A of the Facilitator Guide, Learning Objectives for Case Vignettes, for ideas for discussion points to highlight during the discussion following this activity.*

- It's time to put all of this into practice. You're going to work with your tables and use the case vignette assigned to your table to answer the following questions:
  - Name the protective factors that are apparent in each case. Feel free to speculate about protective factors or make a list of ones you might expect to be present but you aren't sure. Asking families about what works and what hasn't worked in the past is helpful for moving forward.
  - Are there protective factors you want to keep in mind when referring this child and family for additional services and/or treatment?
  - We'd like you to identify what the challenges and barriers for the child and family in your assigned case. How might that family have difficulties accessing services, etc.
  - And finally, we'd like you to come up with a few ways that you would advocate for this family. What would you want to screen for? Start thinking about what planning for services would look like with your family. *[Allow 20 minutes for this discussion. Have a participant at each table briefly report out on what they would do.]*

SLIDE 59
Essential Messages

- As a recap, here are the Essential Messages that we discussed in Module 5.

8. Partner with agencies and systems to ensure earlier and more sustained access to services.
9. Ensure that trauma-informed child-centered services, treatments and systems drive the recovery plan.

SLIDE 60
What Can a Provider Do?

PP 33-34 5 MIN

TRAINER TIP: *This is an Activity slide, which will recur at the end of each Module. This is the opportunity for participants to reflect on their own practice and think concretely about what they can enhance or do differently, based on the information that was just presented to them in Module 5. Participants will be given a checklist to fill out to help guide their reflections. Emphasize to participants that if they feel that the options are too clinically focused, they should create strategies that are relevant to their role.*

- Here are some things that you as a provider can do to address the concepts that we discussed in Module 5. Think about the child you identified at the end of Module 1 who connects you to this work. What can help that child and other children with IDD who have experienced trauma? Let's take a few minutes to think about what you can do specifically in your role and at your organization to address any one of these points. For example, more frequent meetings (e.g., monthly vs. quarterly) may keep the team proactive vs. reactive.
- Pull out your handout titled, ***Action Planning: Essential Messages 8 & 9***. This is your opportunity to think about how you are going to implement the ideas that we just discussed in Module 5, into your daily practice, as soon as you get back to your office. You will see that the handout outlines specific strategies for things that you can do to address the Essential Messages. These strategies were written in SMART objective format (Specific, Measurable, Achievable, Results-Oriented, Timely). Mark an "X" in up to three boxes next to the ideas that you think you would MOST like to emphasize in your daily practice for the Essential Messages. If you would like to create your own strategy, using SMART objective format, you are welcome to do that as well. *[Allow 5 minutes to complete the activity. After activity is done ask 2-3 people to share one strategy they think they would like to implement starting tomorrow.]*

BREAK

Facilitator Notes
Module 6: Provider Self-Care

SLIDE 61
Module 6: Provider Self-Care

- In the last Module we looked at how to enhance protective factors of children with IDD and families through IDD-informed trauma assessment & screening and referral to appropriate trauma-informed services & treatment.
- This Module looks at parent/caregiver and provider needs and the steps to stress reduction and self-care.

SLIDE 62
Module 6: Learning Objectives
What Will I Learn Today?

After completing today's training, you should be able to do the following:

1. Describe the difference between secondary traumatic stress, burnout and vicarious trauma.
2. Identify how burnout develops among providers.
3. Discuss potential sources, warning signs, and effects of secondary traumatic stress and organizational stress.
4. Implement steps to stress reduction and self-care.

SLIDE 63 (OPTIONAL)
Trauma Stewardship

2:16 MIN

TRAINER TIP: ***Optional Video****. This may be a good place to show a light-hearted video about the impact of stress. You might choose to show this video developed by Trauma Stewardship. This 2:16 minute clip is a humorous way to illustrate the benefit of taking a few minutes out for laughter: a fun introduction to the importance of self-care.*

- Source: Developed by traumastewardship.com. Video can be streamed from: https://www.youtube.com/watch?v=tAKPgNZi_as

SLIDE 64
Definitions

- There are multiple ways that people talk about Secondary Traumatic Stress. Let's talk about a few of these.
- It's important to distinguish the difference between the three definitions shown here. There are slight variations in the descriptions that should be understood before diving into a personal self-care plan, as well as a plan to tackle stress in your organization.

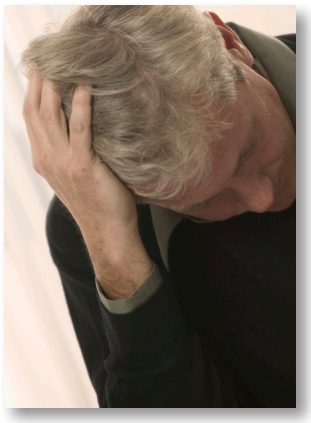
SLIDE 65
Provider Burnout

- Children with IDD and trauma exposure may have challenging behavior. Behavioral problems create significant challenges in *providing safety and support* to providers and consumers, as they often require high levels of supervision and result in increased rates of staff injuries, leading to high staff turnover.

Identifying adaptations that can be made for children with IDD may feel rewarding at times and frustrating at other times.

- Programming for adults and children with IDD often includes intricate behavioral support plans, risk reduction plans, and habilitation plans, each of which requires attention to behavior, skills to teach, and documentation. This is often challenging for even the highly trained behavioral clinician; providers can experience high stress levels and burnout and can feel ill-equipped to manage all the aspects of care.
- The complexity of needs of children with IDD who have experienced trauma can combine to create high intensity jobs:
  - High needs of children
  - High needs of families
  - Multi-agency involvement
  - Administrative demands (paperwork, office management)
  - High caseloads
- Identifying adaptations that can be made for children with IDD may feel rewarding at times and frustrating at other times.
- *High turnover, emotional instability, and provider burnout* lead to reduced physical and emotional safety for youth and staff.

SLIDE 66
Secondary Traumatic Stress



- Many of us unconsciously absorb the traumas of the youth and families that we work with. Every day we hear their stories, and watch the difficulties of those stories play out in front of us.
- For child-serving professionals involved in the care of traumatized children and their families, the essential act of listening to trauma stories may take an emotional toll that can compromise professional functioning and may diminish quality of life.
- As a result, many of us may experience **Secondary Traumatic Stress**, also sometimes referred to as compassion fatigue. Hearing youths' stories and dealing with the aftermath of their traumas, including their behavior, thinking, and emotional responses can lead to the development of traumatic stress reactions.
- The potentially traumatic etiology of the IDD and/or traumatic experience (NICU exposure, other medical trauma, TBI due to accident) and the traumatic aspects of the loss of the idealized child can result in STS and vicarious traumatization for both the parent/caregiver and the provider.
- Providers may feel more angry and distressed when hearing about a traumatic experience of a child with IDD. Hearing these types of stories over and over again may become anguishing or enraging.
- *[Ask participants to respond to the question on the slide.]* Some potential responses might be:
  - Feelings of isolation
  - Fear and/or internalized bias about working with children with IDD
  - Guilt about pushing children with IDD too hard
  - Feelings of helplessness
  - Feelings of resentment due to challenges inherent to working in multiple systems (e.g., lack of communication)
  - Feelings of guilt about things we can do that others can't (e.g., "ability" guilt)
  - Recognition that some types of IDD create more stress for us than others.

SLIDE 67
Potential Sources of STS

TRAINER TIP: *There are animations on this slide, but they are timed, so you do not have to do anything to initiate them.*

- As we pointed out, STS refers to the development of post-traumatic stress symptoms caused by exposure to traumatic material.
- Exposure to trauma can happen in multiple ways:
  - What a child or their caregiver tells you or says in your presence
  - The child's play, drawings, written stories
  - The child's reactions to trauma reminders
  - Media coverage, case reports, or other documents about the trauma

Secondary traumatic stress refers to the development of post-traumatic stress symptoms caused by exposure to traumatic material.

- Take a moment to think about the children and families you work with…
- Many of you have experienced difficult situations that have caused you to lose sleep, worry, or become anxious. Can you name a few? *[Allow two minutes for participants to name a few.]*

SLIDE 68
STS Warning Signs

- Because of the work we do as helping professionals it is easy to overlook symptoms of secondary traumatic stress. The following are some warning signs that indicate you could be experiencing STS.
- **Chronic exhaustion**—you feel as if you don't have the time or energy to do all that needs to be done. You may wonder whether what you are doing constitutes worthwhile work.

It is easy to overlook symptoms of secondary traumatic stress.

- **Disconnection/Empathic Numbing**—you feel so overwhelmed that you shut down or become numb to the stories you hear. You may feel you have lost your empathy.
- **Social withdrawal**—you turn down social engagements, withdraw from intimacy with your spouse, and overlook commitments you have made with your children.
- **Avoidance**—the phone rings or your pager goes off and you think "I'm not answering it." You see your message light beeping and you ignore it. Your alarm clock goes off and you think of all the reasons you can't go in that day.
- *Continues on next slide.*
- **Boundaries**—you compensate by switching into what you believe is high gear. You spend more time at work, take more work home, give up outside work activities to get to work earlier and then leave later. You make executive decisions that may intrude on the work areas or job functions of others because you believe that's more efficient than asking someone's opinion.
- **Anger/Cynicism**—you begin to think there is no hope. You are suspicious of everyone's motives.

- **Diminished Self-Care**—you or your friends and family begin to notice that you are not doing what you used to do to take care of yourself. You may be less concerned about your appearance or exercising.
- **Illness**—you may begin to experience pain or illnesses. Your body is telling you that it is overwhelmed.
- **Survival Coping**—instead of going to that happy hour once a week it becomes a daily ritual on the way home. When our coping mechanisms are significantly challenged and overwhelmed we also experience symptoms similar to those of the children who have had traumatic experiences, whom we serve.
- Now let's take a look at our own warning signs. Pull out the ***Stress Warning Signs*** handout.
- Take a few moments to fill out the short paragraph *[Allow 5 minutes for activity]*
- Is anyone willing to share with the group? *[If no one is sharing, please share your answers]*

SLIDE 69
Effects of STS

- Here's a list of symptoms you can experience when dealing with STS.
- Read through the symptoms on the slide.
- Do any of these resonate? *[Allow 2-3 mins of responses from the audience]*
- It's important to be aware of how STS effects you.

SLIDE 70
Steps to Stress Reduction

PM
P 36
3 MIN

TRAINER TIP: *Participants will read through the **Self Care Options** handout and pick one strategy from each category.*

- Self-care is:
  - Only taking responsibility for job functions you have control over.
  - Finding ways to maintain a positive attitude towards the work despite challenges.
  - The right to be well, safe, and fulfilled.
  - Not an emergency response plan to be activated when stress becomes overwhelming.

- Not about acting selfishly.
- Not about doing more or adding more tasks to an already overwhelming "to-do" list.
- Is most effective when approached proactively, not reactively.

- Self-care does not have to be time-consuming. As nice as it would be to take a long vacation, most of us do not have the time for that. On the sheet being passed around are some strategies for using the time that you do have for self-care. *[Ask participants to pull out the **Self-Care Options** handout and have participants pick one from each category that they can do.]*
  - In addition to these behavioral strategies are cognitive strategies, or considering your beliefs about how you are helping children and supporting families. For example, belief in the effectiveness of a trauma-informed intervention for the child and family you are working with can decrease the effects of STS. Seeing the benefit of your work is as important as getting a break from it.

SLIDE 71
The A-B-C's of Self-Care

- We are going to discuss the A-B-C's of Self-care by talking about what you as an individual can do for yourself.
- Think of self-care as having three basic aspects:
  - Awareness
  - Balance
  - Connection—the "ABC's" of self-care.

SLIDE 72
Awareness

2 MIN

- The first step in self-care is much like the first step a clinician, physician, or mechanic takes in diagnosing a problem. It involves a check-up of your body and mind. You are the only person who can take this first step because everyone's evaluation of stress and personal functioning is different. This step requires you to slow down and focus inwardly to determine how you are feeling, what your stress level is, what types of thoughts are going through your head.
- Self-care begins with awareness. Knowing your warning signs and understanding what works for you and what does not are essential to building and maintaining a sustainable self-care plan. Over the long term, this means building self-care routines and rituals into everyday life, in our personal and professional lives. Over the short term, we can create moments of awareness simply by pausing to take a breath.
- A simple breathing exercise may help you increase your awareness. Follow this guide:

- Sit up straight.
- Take a long, slow deep breath through your nose.
- Blow it out slowly through your mouth.
- While you continue to breath in and out slowly, put your hand on your abdomen, feeling it expand and contract with each breath.
- Continue to breath and put your hand on your chest, feeling it expand and contract with each breath.

- Make yourself aware of the path that the air is taking as it enters and leaves your body.
- Focus on your breathing for at least 2 minutes, noticing how your body responds.

- This is something you can easily do at your desk between meetings or even while sitting in traffic.

SLIDE 73
Balance

P 37 5 MIN

TRAINER TIP: *This is an Activity slide. Please be prepared to facilitate the short activity. Fill out the handout,* ***Balancing Your Self-Care*** *with the group. You are going to ask someone to share, but if people do not speak up please give yours as an example to generate other responses or conversation.*

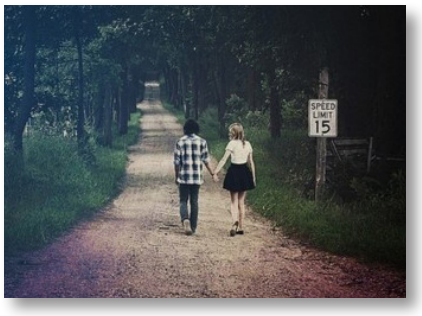
- The second step in self-care is seeking balance among a number of different types of activities. These include work, personal and family life, rest, and leisure. You will be more productive when you've had opportunities to rest and relax.
- Taking care of yourself involves far more than relaxing. It requires that you focus on:
  - Physical self-care
  - Psychological self-care
  - Emotional self-care
  - Spiritual self-care
  - Professional or workplace self-care

Taking care of yourself involves far more than relaxing.

- Pull out your sheet entitled ***Balancing Your Self-Care***. Read through the tool and identify a couple of strategies that you can employ in each area to help reduce stress. *[Allow 5 minutes to complete the activity. After the activity is done ask people to share something they think they would like to do, starting tomorrow, that could help to reduce stress.]*

SLIDE 74
Connection

- The third step in self-care is connection. It involves building connections and supportive relationships with your co-workers, friends, family and community. One of the most powerful stress reducers is social connection.
- Think about ways you can reconnect with your social supports.
  - Schedule a family game night or nightly reading.
  - Hear your partner's repeated request to schedule a standing date night.
  - Plan to see your friends. Go out to a movie or grab dinner.



SLIDE 75
Organizational Stress

- Stress in organizations can also increase your own stress and secondary traumatic stress level.

SLIDE 76
Potential Sources of Organizational Stress

- Exposure to stress can happen multiple ways. Take a moment to think about your organization.
- Many of your places of employment have experienced difficult situations that can lead to organizational stress. Can you name a few? How might these sources of stress contribute to STS? *[Allow 2 minutes for participants to name a few.]*
- Here are a few of the items we came up with. Anything you would add?

SLIDE 77
Impact of Organizational Stress

- Organizations under stress may deal with:
  - **Poor Decision-Making**—sometimes when an organization becomes stressed it is difficult for administrators, supervisors, and staff to make decisions, to think and focus in a way that makes sense and can move the organization to move forward.

- **Mission-less**—under stress an organization may loose sight of its mission. There may be multiple influences that are affecting its ability to carry out its original mission and thus it appears mission-less.
- **Crisis-driven**—the organization sees crises everywhere and attempts to focus its limited resources on a current crisis as opposed to a long-term plan. This can cause programs, policies, or people that were once functioning with support, to become dysfunctional.
- **Punitive**—when an organization becomes crisis-driven, it can also become punitive. Administrators set unreasonable deadlines and expect people to accomplish impossible tasks which, when not met, can lead to punitive consequences.
- **Unsafe**—all of these situations can make an organization feel unsafe. Co-workers may not trust one another, and not trust supervisors. Supervisors may not trust supervisees; administrators and CEOs may not trust government officials or agencies. This can lead to blaming others, angry outbursts, secrets, lack of responsiveness to input, mixed messages, withdrawal, and non-compliance.

SLIDE 78
Impact of Organizational Stress on Providers

- Staff stress can impair organizational functioning in many ways. Here are a few:
  - Increased absenteeism
  - Impaired judgment
  - Unwillingness to accept extra work
  - Low motivation
  - Lower productivity and poor quality of work
  - Greater staff friction
  - Higher staff turnover

- The cumulative exposure to traumatic experiences of the collective workforce can heighten existing organizational stress and further exacerbate secondary traumatic stress among providers.

SLIDE 79
When our organization is stressed, we are all stressed.

- Our organizations are made up of administrators, supervisors, staff, children and families. When the organization is stressed, we are all stressed.
- Stressed organizations can lead to stressed providers who are already dealing with trying to help children who have experienced trauma. This can result in everyone feeling more hopeless, powerless, and cynical, which can result in all of us being more punitive and creating environments which feel physically and psychologically unsafe and thus recreate the very experiences that have proven to be so toxic for the children and families we are trying to help.

SLIDES 80-81
Steps to Organizational Stress Reduction

- There are several ways an organization can help workers commit to self-care, collectively and individually. You may think this doesn't apply to you because you're not in an administrative or management position in your organization. However, you still might have the opportunity to effect change at the organizational level by making suggestions and recommendations to supervisors and management. A critical piece of building organizational support is building a sense of **safety and empowerment**.
- When individuals feel safe and empowered they are far more amenable to change and able to deal with difficulty. Having the support of the entire community, including peers and supervisors, helps everyone to do their jobs better and cope with stress. It is important to **share in both successes and shortcomings** together.
- Another step to reduce stress in an organization is to provide **regular supervision**. Supervision should be scheduled regularly to deal with disciplinary issues, explain new policies, or deal with crisis. Supervision also means listening to the supervisee, hearing what is difficult about his or her job, and when asked, offering practical assistance. Sometimes a team member just needs to vent or process.
  - **Reflective supervision** is the regular collaborative reflection between a service provider (clinical or other) and supervisor that builds on the supervisee's use of her thoughts, feelings, and values within a service encounter.

- **Support open communication**. Most of us don't like to hear news through the grapevine. To the degree possible, all team members should attempt to communicate as directly and clearly as possible.
- **Hold multidisciplinary team meetings**. There is often great wisdom in collective planning and problem solving. When we all try something together then no one of us is totally responsible for its success or failure. Sharing responsibility can decrease stress and increase connectivity.
- **De-stigmatize providers' personal reactions to the work & prioritize self-care** as a necessary part of treatment planning and workplace expectations. Agencies should facilitate team approaches to working with trauma—this increases chances that other people will see problems in colleagues and increases opportunities for obtaining support.
- **Provide mentoring to new professionals**. Remember your first days on the job? For some of you it was likely new and exciting but there also might have been some anxiety or nerves due to the challenges you would face. Pair newer staff with seasoned staff who can share the ways they have dealt with difficult situations. Sharing in the new staff member's perspective can renew a seasoned staff member's energy and interest.
- **Support continuing education**. As budgets are cut it is hard to find training dollars, but there are some free trainings on the internet or in the community. Try to support continuing education for the staff. A great place to do this is through the NCTSN Learning Center where there are over 200 trauma-informed webinars with free CE credit available.

- **Provide respite for providers**. There are many forms of respite. Allow staff the opportunity to take a break after dealing with a challenging situation or client. Express gratitude to a staff member who did a really good job offering to help someone process a particularly problematic case. Another form of respite, is encouraging staff to use their vacation time. Vacation time gives staff a break from the everyday exposure to traumatic situations.

SLIDE 82
Wellness Activities

- Here are some other ideas for reducing stress in your organization—focus on wellness activities.

SLIDE 83
Self-Care Resources

- Here are a few resources you can use as you begin discovering the optimal way to recognize your stress and take care of yourself.
- These resources are listed in the References section of the ***Facilitator Guide*** and ***Participant Manual***.

SLIDE 84
Essential Message

- As a recap, let's review the Essential Message that we just discussed in Module 6.

10. Practice ongoing self-care in order to increase effectiveness in delivering high quality support, services and treatment.

SLIDE 85
What Can a Provider Do?

PP 38-41 15 MIN

TRAINER TIP: *This Module has two handouts,* ***Action Planning: Essential Message 10*** *&* ***Personal Trauma-Informed Practice Action Plan****, to continue the process we have engaged in at the end of each Module of giving participants to reflect on their own practice and think concretely about what they can enhance or do differently. The first handout asks participants to consider the information that was just presented to them in Module 6. The second handout asks participants to go back and review all of the strategies they chose from each module and then pick the top 3. Emphasize to participants that if they feel that the options are too clinically focused they should create strategies that are relevant to their role.*

- Here are some things that you, as a provider, can do to address the concepts that we just discussed in Module 6. Think about the child you identified at the end of Module 1 who connects you to this work. What can help that child and other children with IDD who have experienced trauma? Let's take a few minutes to think about what you can do specifically in your role and at your organization to address any one of these points.
- Pull out your handout titled, ***Action Planning: Essential Message 10***. This is your opportunity to think about how you are going to implement the ideas that we just discussed in Module 6, into your daily practice, as soon as you get back to your office. You will see that the handout outlines specific strategies for things that you can do to address this Essential Message. These strategies were written in SMART objective format (Specific, Measurable, Achievable, Results-Oriented, Timely). Mark an "X" in up to three boxes next to the ideas that you think you would MOST like to emphasize in your daily practice for each Essential Message. If you would like to create your own strategy, using SMART objective format, you are welcome to do that as well.
- Now, pull out your handout titled, ***Personal Trauma-Informed Practice Action Plan***. Go back to the strategies you identified under the Essential Messages at the end of each module (you can refresh your memory by pulling out all of your ***Action Planning*** handouts). Then, select your top three strategies that you want to commit to implementing as part of your Action Plan. Write each of these strategies in the boxes provided below, and in the corresponding box in the right hand column, write in the Essential Message number associated with each strategy. If you are willing, copy your answers on to the duplicate copy of the ***Personal Trauma-Informed Practice Action Plan*** and hand it in. In 3-6 months, we will contact you to ask you if you were able to implement your strategy and if not, why not. *[Allow 15 minutes to complete the activity. After activity is done ask 2-3 people to share one strategy they think they would like to implement starting tomorrow.]*

SLIDE 86
Evaluation of Learning: Day 2

PP 43-45 5 MIN

TRAINER TIP: *This evaluation of learning will be completed at the end of Day 1 & Day 2.*

- Pull out your handout titled, ***Post-Training Evaluation: Day 2***. Please complete it and turn it in before you leave for the day.

SLIDE 87
Remember, You Can Do This Work!

- As we said at the beginning of this training, "you can do this work!" Not only can you do it, children with IDD who have experienced trauma, and their families, need you to do it.
- In his book, *Far From the Tree*, Andrew Solomon eloquently shares powerful stories of ordinary people facing extreme challenges to support his belief that being exceptional is at the core of the human condition—that difference is what unites us. All parenting turns on a crucial question: to what extent should parents accept their children for who they are, and to what extent they should help them become their best selves.

- The premise of this training is that providers have the opportunity, challenge and privilege to partner with parents and caregivers in helping children with IDD who have had traumatic experiences to recover and to become their best selves, to experience great joy and happiness, and to attain a valued and fulfilling life.

SLIDE 88

THANK YOU!

- For more information about child traumatic stress, go to the NCTSN website at www.NCTSN.org or the NCTSN Learning Center for Child & Adolescent Trauma at http://learn.nctsn.org.

Appendix A
Learning Objectives for Case Vignettes

Listed are ideas for learning points to highlight if they do not come up in discussion.

Ivana

- Ivana's case highlights:
  - Risks of international adoption- drug exposure and suboptimal caregiving
  - Global developmental delay and reactive attachment disorder with unknown traumatic exposure and neglect
  - Infant with regulation and social issues as the sign of traumatic stress
  - All social problems are not autism
  - Concerns that early intervention providers might face
- Additional questions/points to consider:
  - Ivana raises questions about the context of the traumatic experience. Traumatic exposure is unknown. For example, what may have happened at the orphanage in Russia? What about potential trauma related to separation from her birth mother? It may not be possible to obtain answers to these questions.
  - Additionally, there is no mention of developmental milestones—is Ivana showing signs of delays in development? What led to the Global Developmental Delay and Reactive Attachment Disorder diagnoses?
  - It may be premature to be rushing to an Autism Spectrum Disorder evaluation: the emphasis appears to be on deficits, with no discussion about how Ivana is doing. Ivana's adoptive mother probably needs help developing a secure attachment with Ivana—this should be the emphasis versus focusing on a diagnosis.

Suzie

- Suzie's case highlights:
  - Ensuring supportive services for child with autism
  - Addressing domestic violence and developmental services
  - Pressures added to family dynamic/trauma with a child with developmental problems
- Additional questions/points to consider:
  - There is a lot of overlap between IDD and trauma diagnoses. It is oftentimes difficult to determine whether responses are related to the IDD or the trauma. Suzie's case is a good example of this.
  - Parents may need education about autism.
  - Is Suzie safe? Extent of domestic violence needs to be assessed.

Appendix A
Learning Objectives for Case Vignettes

Joshua

- Joshua's case highlights:
  - Risk of social problems and borderline IQ for abuse
  - Signs of sexual abuse
  - Working with affluent communities and accessing private resources
  - Ensuring supportive services for child with autism
  - Treatment modifications for poor social engagement
  - Chronic trauma
- Additional questions/points to consider:
  - It may be challenging to communicate or educate Joshua about the abuse, due to his cognitive limitations.
  - The independent school that Joshua currently attends may not be the best placement for him. He might better from a placement with a strong social skills and emotional training curriculum (e.g., The Circles Curriculum).

Steven

- Steven's case highlights:
  - Significant medical issues in a high risk premature infant with brain injury
  - Early trauma and young developmental age behavioral presentation
  - Service connection for medical foster care settings
- Additional questions/points to consider:
  - Steven's case also demonstrates a lot of overlap between IDD and trauma diagnoses. He has multiple traumas that have occurred throughout his life.
  - Where is Steven's dad? Is he involved? He was re-deployed before Steven's first birthday, but Steven is now 10. As assessment of relationships and/or significant individuals in Steven's life may be helpful.
  - Did Steven receive any early intervention services in the group medical foster home?
  - What are ideas for providing support to Steven's mom? Is she involved? Is reunification part of the plan?
  - Steven's case is a good example of "all behavior is communication." What is Steven trying to communicate through his behavior?

Appendix A
Learning Objectives for Case Vignettes

Jacqueline

- Jacqueline's case highlights:
  - Traumatic brain injury (TBI) in the setting of a learning disability
  - Differentiating which symptoms are from TBI, post-traumatic stress, or typical adolescence
  - Recognizing depressive symptoms in a complex presentation
  - Seeing the potential intervention settings beyond the medical and mental health
- Additional questions to consider:
  - Jacqueline's case demonstrates the importance of obtaining a clear history. For example, what happened before the traumatic experience?
  - What about potential traumatic responses the grandmother may be having? What are ideas for providing support to her?
  - Are there language and cultural issues to consider that may be adding to the complexity?

Justin

- Justin's case highlights:
  - Trauma in community settings for young adult with ID
  - Behavioral signs of abuse
  - Foster care and conservatorship resources in ID
- Additional questions to consider:
  - How are Justin's physical limitations impacting him?
  - Justin has a significant strength in that he has been placed with a loving couple.
  - The traumatic experience led to an increase in anxiety and agitation. Are trauma reminders at play?
  - How are his social skills?

Appendix B
Videos

Please note that some of these videos are available in the public domain and others need to be purchased in order to use the recommended clips. The * indicates films that need to be purchased. Be sure to read through your Facilitator Notes to know the different clips to use from the videos below. Additional videos on various types of disabilities can be found in the Supplemental Materials (Tab 5).

Changing the Course of Children's Lives By Changing the Course of Their Care

This video is an NCTSN Public Service Announcement about child trauma and its effects on the children and families we serve: https://vimeo.com/67735273

All Behavior is Communication—Looking Behind Behavior

This is a Ralli Campaign video in which Jake's parents describe how his behavior deteriorated when he started 1st grade. Jake tells us why he used to crawl under the table in the classroom. You'll learn how things changed for him once he gained the right support for his language difficulties. This video is a good example of why it is important to recognize that all behavior is communication: https://www.youtube.com/watch?v=WTySmn_-X80

*ReMoved**

ReMoved follows the emotional story through the eyes of a young girl taken from her home and placed into foster care. This trailer may be an impactful way to introduce responses to traumatic experiences by highlighting the thoughts and feelings she is experiencing, how her behavior may be a reaction to trauma reminders, and the hope that she can recover and will be loved: https://www.youtube.com/watch?v=lOeQUwdAjE0. The entire film is available for purchase at www.removedfilm.com

*Ask Us Who We Are**

This documentary focuses on the challenges and extraordinary lives of youth in foster care. The film is a reflection on loss and the search for belonging and finding family. Although the film highlights the heartbreak that many foster care youth carry with them as they move through their lives, the documentary also reveals the tremendous strength and perseverance that grows out of their determination to survive and thrive: http://kingdomcounty.org/portfolio-items/ask-us-3/

Enhancing Child Well-Being, Resilience & Recovery—Finding My Strengths

This is a Ralli Campaign video in which Harry, a student with a speech and language impairment, shares how he felt like an outcast in the classroom and wondered why he was finding things so difficult. The film tells how nurturing of Harry's strengths proved to be as important as supporting his language skills. It also tells about how happy he is now and how positive he is about his future: https://www.youtube.com/watch?v=J2eR0Te6wFA

Appendix B
Videos

The Promise Video

This is an NCTSN video developed to provide information about the impact of child sexual abuse, to emphasize the importance of including parents/caretakers in treatment, and to highlight the need for children in therapy to learn specific skills to deal with what has happened to them and to talk about the details of their sexually abusive experiences. Available to stream at https://vimeo.com/44524868. Available to order free of charge at http://www.nctsnet.org/trauma-types/sexual-abuse#q6

*Adapting Trauma-Focused Cognitive Behavior Therapy**

This is a video of Brian Tallant, MS, NCC, LPC giving a presentation on how to adapt trauma-focused cognitive behavior therapy (TF-CBT) for individuals with disabilities, at *Breaking the Barriers: Forming Cross System Partnerships to Effectively Serve Individuals with Mental Illness and Intellectual Disabilities* conference in Long Beach, California. Available for purchase at http://ddd.uwo.ca/resources/BreakingThe%20BarriersDVDOrderForm.pdf.

Trauma Stewardship

This video discusses struggling with secondary trauma, compassion fatigue or simply the weight of caring for others. Caring for yourself under such circumstances often requires extra support, wisdom, and a dose of humor: https://www.youtube.com/watch?v=tAKPgNZi_as

Experiences Build Brain Architecture

This video is from the Harvard Center on the Developing Child. It discusses how the basic architecture of the brain is constructed through a process that begins early in life and continues into adulthood. Simpler circuits come first and more complex brain circuits build on them later. Genes provide the basic blueprint, but experiences influence how or whether genes are expressed. Together, they shape the quality of brain architecture and establish either a sturdy or a fragile foundation for all of the learning, health, and behavior that follow. Plasticity, or the ability for the brain to reorganize and adapt, is greatest in the first years of life and decreases with age: http://developingchild.harvard.edu/resources/multimedia/videos/three_core_concepts/brain_architecture/

Multiple Transitions: A Young Child's Point of View on Foster Care & Adoption

This video attempts to distill what children would teach us, if they had the chance, about what being moved around feels like, how and why their behavior begins to change, and what happens to their availability for new attachment: http://www.infant-parent.com/products/multiple-transitions-a-young-child-s-point-of-view-on-foster-care-and-adoption

Appendix B
Videos

Exposure to Violence on a Child's Developing Brain
This video was products by the CA Attorney General's Office to offer information about the effects of domestic violence on young children:
https://www.youtube.com/watch?v=brVOYtNMmKk

Children, Violence & Trauma: Treatments that Work
This Office for Victims of Crime video discusses the serious consequences of children's exposure to violence and trauma, such as substance abuse and mental health and behavioral problems, and the increased severity of symptoms experienced by children who have suffered multiple forms of victimization. It also features some of the evidence-based treatment strategies for children and their families that researchers and experts consider effective:
https://www.youtube.com/watch?v=3EyvaEk0K-k

Through Our Eyes: Children, Violence & Trauma
This Office for Victims of Crime video discusses how violence and trauma affect children, including the serious and long-lasting consequences for their physical and mental health; signs that a child may be exposed to violence or trauma; and the staggering cost of child maltreatment to families, communities, and the Nation. Victims lend their voices to this video to provide first-hand accounts of how their exposure to violence as children affected them:
https://www.youtube.com/watch?v=z8vZxDa2KPM

Telling It Like It Is: Foster Youth & Their Struggle For Permanency
This National Institute for Permanent Family Connectedness video highlights different digital stories about children in the child welfare system and their struggles to connect with foster families due to trauma. Two stories are available to watch online at http://familyfinding.org/resourcesandpublications/digital_stories.html. The complete video of all ten stories is available free of charge familyfinding@senecacenter.org.

Brain Hero
This video, developed by the Center on the Developing Child at Harvard Center and USC's Creative Media & Behavioral Health Center, depicts how actions by a range of people in the family and community impact child development:
https://www.youtube.com/watch?v=s31HdBeBgg4

Appendix C
How to Embed Video

Videos can be an effective way to illustrate instructional points. Due to copyright legalities, most of the identified video clips have not been included on the CD. However, Appendix E provides information about where to obtain these videos and how to clip and embed prior to training.

Embedding a Video

PowerPoint 2007

1. Open your PowerPoint to the slide you need to embed your YouTube video into. When you do this check to make sure you have an option for Developer in your ribbon where you see Home, Insert, Design, etc. If you do not see this option, we need to open it up.
2. Click on the PowerPoint logo in the upper left hand portion of your screen. The same button you hit when you want to print. Click that logo.
3. On the bottom of the box that appears you will see PowerPoint Options. Click that.
4. What you will see if a box with Popular, Proofing, Save, Advanced down the left hand side. Under the Popular tab you will see a place, on the right hand side, to click Show Developer tab in the ribbon. Make sure this is checked marked. Once it is checked, click ok at the bottom of the box to exit. You now should have the Developer tab option in your ribbon.
5. Open YouTube and find the video you need to embed. At this point you will have PowerPoint open and YouTube open. (You will need an internet connection for this step).
6. To embed a YouTube video properly into a PowerPoint presentation you will need the URL of the video. Once you find the YouTube clip you need, depending on how your YouTube opens you will either see:
    a. The option to choose URL or Embed this clip to the right of the actual clip you are watching. If this is what you see you will need to highlight and copy the URL ***NOT*** the embed link.
    b. If you do not see this option to the right of your clip you can highlight the URL at the top of the screen.
7. Once you highlight this link you will need to copy the link. This can be done by pressing Control C on your PC or Command C on your MAC or right click and find the work Copy in your scroll down bar.
8. Once you have the link copied you are ready to move to PowerPoint. Go back to your slide where you would like to embed this clip and click on the Developer tab.
9. You will see options such as Visual Basics, Macros, Macro Security, etc. Next to these options there are several icons for you to choose from, these are Control options. You will need to click on the icon that resembles a wrench and hammer crossing over one another. This is the More Controls options.
10. Once you click on this icon a box will appear with options for you to choose. Scroll down towards the bottom and select the Shockwave Flash Object and click ok.

11. When you select this your mouse will change to a small cross. This allows you to draw a box on the slide you wish to place the video into. You need to choose where you would like the upper left corner of the video box to be, click and move the mouse down to the bottom right. You will see a box appear as you do this. When you let go of the mouse the box will fill with a large X from the corners of the box. You've just created your flash object.
12. Now we are going to embed the video. Right click anywhere on the Flash Object you just created and select the Properties option. A detailed Shockwave Flash window will appear on your screen. There is a lot of information here, but you only need to pay attention to the Movie, Loop, and Playing categories.
13. Take your YouTube Video URL you copied and paste it next to where it says Movie in the Shockwave Flash window. You are not done. You are going to have to modify this link a bit. You need to delete the word watch anywhere in this URL. If the URL contains a ? please replace with a backslash /
14. Once you have modified your URL. Click in the box to the right on the Loop category. You will see a drop down menu with True or False. You need to click False. This will stop the video after it is played. If you do not change this setting the video you embedded will loop until you change the slide.
15. Once you have changed this category, click in the box to the right of the Playing category. You will see a drop down menu with True or False. You need to click False. This will allow you to click on the video to play it at a time of your choosing. If you leave this option the clip will begin playing once get to this slide.
16. Once you have made these three changes exit out of the Properties box by clicking the x in the upper right hand corner of this box. You will see the slide looks like nothing has changed, but when you play the slideshow the video will appear on your computer screen.

For Visual Assistance see-
Embedding a YouTube Video into a PowerPoint Presentation 2007-
http://www.youtube.com/watch?v=hChq5drjQI4

Appendix C
How to Embed Video

PowerPoint 2010

1. Open your PowerPoint to the slide you need to embed your YouTube video into.
2. Open YouTube and find the video you need to embed. At this point you will have PowerPoint open and YouTube open. (You will need an internet connection for this step).
3. To embed a YouTube video properly into a PowerPoint presentation you will need the Embed code of the video. You will see under the actual clip a button to click that says Share. When you click this link you will see the URL displayed. Next to the URL there are Embed and Email button options. Press the Embed button to obtain the embedding code. You will see this appear.
4. Highlight and copy the code. This can be done by pressing Control C on your PC or Command C on your MAC or right click and find the work Copy in your scroll down bar.
5. Once you have the link copied you are ready to move to PowerPoint. Go back to your slide where you would like to embed this clip and click on the Insert tab.
6. Several options will appear on the ribbon, such as Table, Picture, Clip Art, etc. On the far right of this ribbon there is an option for Video. Click this option.
7. A drop down menu will appear. You need to choose Video from Web site.
8. A pop up box will appear. This is where you need to paste your embed code. Do this by pressing Control V on your PC or Command V on your MAC or right click and find the word Paste in your scroll down bar.
9. You will see the code appear in the box. If the code does not appear, try to copy it again from YouTube. Once you see the code appear press the Insert button to exit the box.
10. A black box will appear in your slide. Choose one of the corners to enlarge or move the box to where you would like it on the slide. You can right click anywhere on the box to see a menu box. In this box you have the option to preview the video to make sure it embedded correctly.

For Visual Assistance please see-
Embedding a YouTube Video into a PowerPoint Presentation 2010-
http://www.youtube.com/watch?v=lihAMHeLC60

Appendix D
Transfer of Learning Follow-Up Form

I. Interview Information: (To be filled in by interviewer before or at the end of the interview.)

Participant Name: _____

Training Date: _____

Interviewer Name: _____ Interview Date: _____

II. Introduction:

"Hello. My name is . I'm part of *(insert organization name)*. I'm conducting a follow-up evaluation with everyone who attended the training, *The Road to Recovery: Supporting Children with IDD Who Have Experienced Trauma* in *(insert place)* on *(insert date)* to find out how useful the training has been and what we might do to improve it. As part of the course, you completed a Personal Trauma-Informed Practice Action Plan and I'd like to talk to you about how the implementation of the plan went. This will take about 15 minutes."

III. Review actions planned:

"If you'll remember, as part of *The Road to Recovery* training you were asked to complete an Action Plan. The facilitator asked you to think about ways you could apply what you learned to improve your own practice by using trauma-informed and trauma sensitive strategies with children and families served by your agency, and to write down a few concrete actions you planned to take to do this. For each of your planned actions, I'd like to ask you about what you were able to do, what kind of impact you think your actions had, and what factors helped or hindered you.

"I would like to review what you wrote in your plan with you. It's probably been a while since you attended *The Road to Recovery* training, and you may have forgotten what you wrote. I have a copy of your Action Plan and can review it with you. Would you like me to do that?" *(Have the original plan handy to remind the person, if necessary, of what they wanted to address.)*

1. Do you remember your Action Plan?

☐ Remembers/has Action Plan ☐ Does not remember/did not do Action Plan

Then, ask the former participant the following questions, and complete this form as you do so:

"I'd like to begin with your first strategy from your original Action Plan."

2. It appears that the first strategy on your Action Plan was (write in strategy here):

_____

_____

a. For this first strategy, would you say that you (write an "X" in the applicable box):

- ☐ Were able to implement the strategy as planned
- ☐ Partially implemented the strategy
- ☐ Implemented a different but related strategy
- ☐ Were not able to implement the strategy at all *(if not at all, skip to question "b" below)*

If any of first three boxes were checked, ask:

i. Could you describe for me what you did? (try to get specifics/examples)

_____

_____

ii. What effect(s) do you think your strategy had (e.g., on practice/clients, agency, community,
etc.)?

iii. Were there any factors that helped you implement your strategy? If so, what were they?

- ☐ Support from supervisor
- ☐ Support from colleagues/peers
- ☐ Other:

Please describe further: _____

_____

_____

b. What, if any, barriers exist that hindered you in implementing this strategy? If so, what were they?

- ☐ Lack of support from supervisor
- ☐ Lack of support from colleagues/peers
- ☐ Time/competing priorities
- ☐ Other: _____

Please describe further: _____

_____

_____

3. The second strategy on your Action Plan was (write in strategy here):

_____

a. For this second strategy, would you say that you (write an "X" in the applicable box):

- ☐ Were able to implement the strategy as planned
- ☐ Partially implemented the strategy
- ☐ Implemented a different but related strategy
- ☐ Were not able to implement the strategy at all *(if not at all, skip to question "b" below)*

If any of first three boxes were checked, ask:

i. Could you describe for me what you did? (try to get specifics/examples)

_____

_____

ii. What effect(s) do you think your strategy had (e.g., on practice/clients, agency, community, etc.)?

iii. Were there any factors that helped you implement your strategy? If so, what were they?

- ☐ Support from supervisor
- ☐ Support from colleagues/peers
- ☐ Other: _____

Please describe further: _____

_____

_____

b. What, if any, barriers exist that hindered you in implementing this strategy? If so, what were they?

- ☐ Lack of support from supervisor
- ☐ Lack of support from colleagues/peers
- ☐ Time/competing priorities
- ☐ Other: _____

Please describe further: _____

_____

_____

4. The third strategy on your Action Plan was (write in strategy here):

_____

_____

a. For this third strategy, would you say that you (write an "X" in the applicable box):

- ☐ Were able to implement the strategy as planned
- ☐ Partially implemented the strategy
- ☐ Implemented a different but related strategy
- ☐ Were not able to implement the strategy at all *(if not at all, skip to question "b" below)*

If any of first three boxes were checked, ask:

i. Could you describe for me what you did? (try to get specifics/examples)

_____

_____

ii. What effect(s) do you think your strategy had (e.g., on practice/clients, agency, community, etc.)?

iii. Were there any factors that helped you implement your strategy? If so, what were they?

- ☐ Support from supervisor
- ☐ Support from colleagues/peers
- ☐ Other: _____

Please describe further: _____

_____

_____

b. What, if any, barriers exist that hindered you in implementing this strategy? If so, what were they?

- ☐ Lack of support from supervisor
- ☐ Lack of support from colleagues/peers
- ☐ Time/competing priorities
- ☐ Other: _____

Please describe further: _____

_____

_____

5. Which of the strategies do you feel were the easiest to implement in everyday practice? Please state reasons:

6. Which of the strategies do you feel were the most difficult to implement in everyday practice?
Please state reasons:

7. What, if any, changes did you make in your practice that were a result of what you learned about trauma, but were not part of your initial Action Plan? If so, please provide examples:

8. What, if any, recommendations might you have about facilitating the inclusion of trauma-informed/trauma-sensitive strategies into ongoing daily practice?

9. Do you have any comments about the Action Plan process or this follow-up?

10. Do you have any other comments you would like to share with the project staff?

Appendix E
Optional Follow-Up 1-3 Months Following Training: Sample Letter

*(To be placed on organizational letterhead and distributed to training participants **IF** facilitators are following up with participants on their action plans after training)*

(Date)

Dear Training Participant:

(Insert name of county) has begun a process of evaluating *The Road to Recovery* training in order to improve its effectiveness and relevance to your needs. To do that, we need your help.

As part of the evaluation you will be asked to engage in an action planning process before leaving the training today. Throughout the day you will be given worksheets for the Essential Messages described in the training. Each sheet will have several strategies you could use in practice with families and children with IDD who have experienced trauma. We will be asking you to check off the strategies you are most interested in implementing on these worksheets.

At the end of the day you will be asked to choose three strategies from these worksheets for your final Trauma-Informed Practice Action Plan. These will be the strategies you feel you can commit to implementing in your practice. **(Insert name of organization) (or other)** staff will be contacting you x months after training to talk about what changes you were able to make as a result of your participation in this training and Action Plan. They will also be asking for information about facilitators and barriers that you experienced and general feedback on the training.

This evaluation has two purposes:

1. To see if the training has been effective in getting its points across and increasing the groups' knowledge of trauma-informed practice strategies for working with children with IDD and their families; and

2. To get feedback about transfer of knowledge to practice.

Our purpose is to evaluate training, NOT the individuals participating in the training.

In order to conduct a follow-up interview with you we will need your contact information. We are asking that you put your name, email and telephone number/extension on your final Action Plan form. Individual information will only be used to reach you for a follow-up interview. Once this is done, your individual responses will be combined into categories with like responses, and only category information will be reported. Occasionally, it is helpful to make a point to include a specific quote or example from the interviews. If this is done no identifying information will be attached to the quote. Identifying information includes not just your name but any information (e.g., job title) that applies only to you and could identify you.

(If the organization wants, they could also have the interviewer ask permission during the interview to use any especially good examples or quotes. If they do, add: "If the interviewer would like to use a quote or example that you have provided, he or she will ask your permission during the interview.")

Your help with this evaluation process is greatly appreciated. Your feedback will be instrumental in helping to improve training for future participants and our knowledge of effective practice strategies for children and families experiencing trauma. If you have any questions about the evaluation or how the data you provide will be used, please

contact_____; by e-mail at _____, or by

telephone at _____.

Sincerely,

(Name here)

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