

# THRIVING



Helping Adults with Intellectual and  
Developmental Disabilities Heal and Thrive  
Following Trauma

FACILITATOR GUIDE

# ACKNOWLEDGEMENTS

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This project would not have been made possible without the support and hard work of many people and organizations. These materials have been adapted with permission from “The Road to Recovery Toolkit: Supporting Children with IDD Who Have Experienced Trauma” developed by the National Center for Child Traumatic Stress and the National Child Traumatic Stress Network and a national selection of experts in trauma and IDD. The toolkit is an excellent resource for providers of children with IDD.

This project would not have been possible without the funding of the WITH Foundation. The WITH Foundation works to promote comprehensive healthcare for adults with developmental disabilities that meets their unique and fundamental needs.

The chair would like to extend a heartfelt thank you to the Advisory Board:

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# INTRODUCTION

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Welcome to Thriving: Helping Adults with Intellectual and Developmental Disabilities Heal and Thrive Following Trauma. Thank you for your interest in facilitating a Thriving Workshop in your own organization or community and your dedication to supporting people with intellectual and developmental disabilities who have experienced trauma.

This workshop is an introduction to trauma-informed concepts and resources. Trauma-informed services are those that focus on awareness of the impacts of trauma and practices designed to provide safety and empowerment to those who have experienced trauma.

Trauma-informed care is a universal intervention that benefits everyone – organizations, service providers, and people supported. Depending on your role, you may wish to further your training to be able to provide more trauma-sensitive or trauma-specific services. This training will provide some recommendations for resources to further your training.

This Facilitator Guide is part of the Thriving Toolkit, which also consists of a Participant Manual and Slide Deck. Together, they are designed to teach basic knowledge, skills and values about working with adults with intellectual and developmental disability (IDD) who have had traumatic experiences, and how to use this knowledge to support the person's safety, well-being, happiness, and recovery through trauma-informed practice.

The toolkit was designed to support dissemination and implementation of trauma-informed care by providing complete easy-to-use materials so that anyone can provide the Thriving training in their own community and/or organization. The complete toolkit can be downloaded from the Thriving website.

These materials have been adapted with permission from “The Road to Recovery Toolkit: Supporting Children with IDD Who Have Experienced Trauma” developed by the National Center for Child Traumatic Stress and the National Child Traumatic Stress Network and a national selection of experts in trauma and IDD. The Thriving Toolkit provides up-to-date tools and resources that are developmentally appropriate for adults with IDD. If you are interested in the Road to Recovery Toolkit or learning more about child trauma the National Child Traumatic Stress Network Learning Center (<https://learn.nctsn.org/>) is a wonderful resource.

## **Organizing your Own Workshop**

If you are providing a workshop for your own organization, you may already know your audience, have a space or virtual platform to use, and how much time you have. You may still need to consider whether to have one large group or multiple groups, or whether it might be beneficial to mix up supervisors and supervisees. This will all depend on the organizational culture. You may also consider inviting participants from other organizations with which your organization collaborates. Cross-training and cross-system collaboration are vital to effective service delivery, and this is especially true for trauma-informed care for people with IDD. This workshop may be a great opportunity to build or strengthen these collaborations.

If you are hosting a workshop in your community at large, you will need to determine workshop size, length, frequency, and venue. Reach out to local advocacy organizations for support and/or suggestions. They may be able to provide a venue and help advertise the course.

## **Organization of this course**

This course contains six modules. Each module contains a set of learning objectives and are built around 10 Essential Messages. These Essential Messages are the key take-home messages of the training. Each module also includes a few individual and group activities to help participants apply the concepts to their own role and context. If you are providing a workshop for participants from multiple organizations and/or from multiple training backgrounds, we recommend assigning participants into mixed groups so that they can cross-train and share their experiences and learn from the experiences of others. At the end of each module, participants will complete an Action Planning activity where they will identify actionable steps they can take to apply the trauma-informed essential messages their own work. At the end of the training, they will create a Personal Trauma-Informed Action Plan where they will identify the top 3 action steps that they can commit to implement in their work.

## **Breakout groups**

There are several group activities in the Thriving workshop. These are great opportunities for participants to learn from each other. To the extent possible, we recommend assigning people to tables/breakout rooms for these activities. If you know the participants before the workshop or you have pre-registration, assign people to groups with the goal of having a mix of experience levels and disciplines at each table. For example, a table might include a direct support professional, a social worker, a mental health counselor, and an administrator. Each person will be able to share their experiences and insights from their discipline with the others. This deepens learning and encourages cross-system collaboration. If you are hosting an in-person workshop, arrange 4 – 6 participants around tables, but be mindful of the placement so that participants can sit comfortably and face the presentation screen. If hosting a virtual meeting, make use of the breakout room functionality available on most platforms.

## **Workshop Size**

The Thriving Workshop is designed to be interactive. It works best when participants can work together in small groups and ask questions throughout. Smaller groups of 30 or fewer people will be more likely to encourage discussion and questions. When registering people for the workshop, you may consider allowing more people to register than you plan. Many people are eager to sign-up but competing commitments or patient emergencies are common and you will likely have several people cancel or no-show. Do not be discouraged!

## **In-person Versus Virtual Workshops**

The Thriving Workshop was originally designed to be an in-person workshop. There are many strengths to this format. Participants are physically present, which increases the likelihood that they will be mentally present as well. Being in-person also increases participant engagement with each other in the small groups, during the presentation, during breaks, and with the facilitator. On the other hand, in-person workshops may be difficult to travel to if you are trying to attract providers from a large catchment area, such as across the state. This is especially true if you are hosting a multi-day workshop.

Virtual workshops have the benefit of ease of access for many people (although not all). There may be some interested participants who do not have access to sufficient internet or technology or may not be familiar with the webhosting platform (e.g., Zoom or Google Meetings). If you host a virtual workshop, we recommend familiarizing yourself with the platform, practice screen sharing and using breakout rooms, and plan to spend time at the beginning to review the technology with participants. The trade-off with virtual workshops is that distractions may be more common as people may try or need to "multi-task" during the workshop, taking calls, checking emails, etc..

There is no right or wrong format. We have successfully provided in-person and virtual workshops, but it can be helpful to consider the trade-offs inherent with both formats.

## **Breathing life into Thriving**

This facilitator guide is designed to be implemented flexibly rather than prescriptively. While knowledge and experience in related fields will be helpful in providing meaningful real-life examples and facilitating discussion, they are not required for facilitating a workshop. We aimed to provide useful background information for the facilitator in the slide notes so that even facilitators with limited background experience will be able to provide the Thriving Workshop.

At the same time, this must be balanced with keeping the information concise and digestible for participants. Facilitators should not feel compelled to read the slides or the notes verbatim. This can result in a lifeless presentation. Instead, use the facilitator notes as a suggestion or jumping off point. Facilitators should familiarize (not memorize!) themselves with the content, watch the recommended videos, and read background articles so they can speak naturally. If you have not attended a Thriving

Workshop, you are encouraged to complete the online course before providing your own to help familiarize yourself with the materials. You are also encouraged to share your own experiences (taking care to respect the privacy of any actual clients or patients). Be sure to pause frequently throughout the presentations to elicit questions or examples from the participants.

## Customizing the Content

The full workshop was designed for a full 2-day workshop. It aims to cover a wide breadth of information with considerable depth, although the topic could certainly span and entire graduate program! If two-days are not feasible for your audience, you may consider abbreviating the material or breaking the modules up in to more but smaller sessions. For example, you may consider hosting a “lunch-time learning” course of a week or two of one-hour sessions.

You may edit the slide deck to customize them for your workshop and audience. For example, you may change some images, delete some slides, or make changes to the text. Depending on your audience, some material may be briefly reviewed or skipped altogether. If you know your audience and know that they are already knowledgeable of IDD, you may consider abbreviating the section on IDD and Development. If your audience is primarily trauma-professionals who may not have experience with IDD, you may cut down on the generally trauma content in Module 3 and focus more on how diagnostic criteria for trauma-related conditions and treatment approaches are adapted for people with IDD in Module 5. See Table 1 for recommendations of prioritized content based on knowledge of the topics.

We ask that you indicate that materials have been modified from the original and that you retain the acknowledgement slides at the beginning and end of the slide deck that thank those who have dedicated significant time, effort, and funding of the project.

**TABLE 1. PRIORITIZED CONTENT BY AUDIENCE BACKGROUND**

	IDD service providers and advocacy organizations	Mental health service providers	Mixed audience or limited knowledge of IDD and mental health
Module 1	✓	✓	✓
Module 2		✓	✓
Module 3	✓		✓
Module 4	✓		✓
Module 5		✓	✓
Module 6	✓	✓	✓

# EXAMPLE SCHEDULE

Below is an example schedule, implementing the full workshop. You may consider modifications such as more frequent, but shorter breaks, shorter or longer lunch period, or spending more time on certain modules and less time on others depending on your audience.

DAY 1	
9:00 am - 9:30 am	Welcome and Introductions
9:30 am - 10:30 am	Module 1: Setting the Stage
10:30 am - 10:45 am	BREAK
10:45 am - 12:15 pm	Module 2: Development, IDD, & Trauma
12:15 pm - 1:15 pm	LUNCH
1:15 pm - 2:30 pm	Module 2 (continued) Module 3: Traumatic Stress Responses in People with IDD
2:30 pm - 2:45 pm	BREAK
2:45 pm - 4:00 pm	Module 3 (continued)
4:00 pm - 4:30 pm	Wrap up Day 1
DAY 2	
9:00 am - 10:30 am	Module 4: Well-Being & Resilience
10:30 am - 10:45 am	BREAK
10:45 am - 12:00 pm	Module 4 (continued) Module 5: IDD & Trauma-Informed Services & Treatment
12:00 pm - 1:00 pm	LUNCH
1:00 pm - 2:30 pm	Module 5 (continued)
2:30 pm - 2:45 pm	BREAK
2:45 pm - 4:00 pm	Module 6: Provider Self-Care
4:00 pm - 4:30 pm	Wrap up Day 2



# Materials

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## **Slide deck and Facilitator Notes**

The PowerPoint slide deck includes the same presenter notes included in this manual. The notes are provided in both places depending on your personal preference or the set up of your technology. Ideally, you will be able to see the “Presenter View” on a separate monitor from the screen that the participant see. If you are unfamiliar with PowerPoint Presenter View, a quick internet search for how to set up PowerPoint presenter view for your PowerPoint version and operating system should help.

We recommend having a print-out of the Facilitator Guide on hand, regardless, in case of unexpected technological issues.

## **Advertising Toolkit**

To support you in advertising your Thriving Workshop, we have created advertising templates that you can modify and download with a free account on Canva. These include printable flyers and trifold brochures and social media posts. These can be found at the Thriving website.

## **Participant Manual**

The Participant Manual is available to download on the Thriving website. It contains thumbnail copies of the slides and space to take notes. The worksheets that correspond to the individual and group activities are embedded in the appropriate place in the slides to make it easier for the participants to locate the appropriate sheet at the appropriate time. If you make substantial changes to the workshop, you may consider re-printing a “notes pages” view of the revised slide deck.

If you are hosting an in-person workshop, it is recommended that you provide participants with printed manuals. The manual can be professionally printed and bound, printed and put in a folder, or just printed on plain paper and stapled. If you are hosting a virtual workshop, be sure to email the manual or provide a download link with plenty of time for participants to have the manual downloaded and printed before the workshop.

## **Optional Evaluations**

Included at the end of this Facilitator Guide is a set of course evaluations that you may consider using for feedback from participants. If you plan to host more than one workshop, this feedback can be valuable for improving the workshop.

## Thriving Card and Board Games

Module 4 includes a group activity to get participants thinking and talking about risk and protective factors and how they might work within their role to help a hypothetical client exhibiting the given risk or protective factor. The card game is designed for in-person workshops, whereas the board game is designed for virtual workshops.

**Card Game.** The cards for the card game can be printed on standard business card paper found at any office supply store. If your budget is limited, you may print one set for each group/table at the workshop. If funding is available, you might consider providing each participant with a set so that they may share the activity with others in their organization.

### *Play Instructions*

- Divide the deck into a deck of risk cards and a deck of protective cards. Deal 5 protective cards to each person. Place the risk cards in the center.
- Select someone to be the judge first. The judge draws a risk card and reads it aloud.
- Everyone picks one of their protective cards that they think will best address the risk and passes it face down to the judge.
- The judge reads the possible solutions and picks their favorite and the group discusses the ideas.
- The player whose card is selected keeps the risk card they have won face down on the table in front of them to keep score.
- Everyone draws a new protective card to maintain 5 cards, reshuffling the discard pile as needed.

**Board Game.** The board game can be accessed at [http://tiny.cc/THRIVING\\_boardgame](http://tiny.cc/THRIVING_boardgame). To play in a virtual workshop, give the participants the link to the board game before splitting up into their breakout rooms. One person from each breakout room will need to be the host and be willing to share their screen. Ideally, it would be whoever has the best internet connection and/or is most familiar with screen sharing. Once in the breakout rooms, each game host will open the board game link and share their screen.

### *Play Instructions*

Each participant will choose a token and take turns rolling the dice, moving the number of spaces, and drawing a card. The host will have to perform the actions for everyone. Each card presents a risk or protective factor. If it is a protective factor, they will be asked in what way does it act as a protective factor against the effects of trauma. If it is a risk factor, they will be asked what they can do in their role to address the risk factor or enhance a protective factor for this person.

# Recommended Videos

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The materials in the Thriving Workshop can be supplemented with additional audio and video. They can be used to demonstrate a concept “in the real world,” serve as a guest expert, and/or allow participants to hear directly from people with IDD, caregivers, and/or service providers. They also break up the monotony of the lecture. Workshop participants often comment on the value of the videos in the workshops and sometimes stated that they wished there were more videos. Below are some examples of videos that have been used in the workshops that you may consider using in your workshop. You are also encouraged to find others to use in place of or in addition to these.

**“The Sexual Assault Epidemic No One Talks About”** by Joseph Shapiro

This is an audio of the radio series “Abused and Betrayed” that revealed the unpublished Department of Justice records that showed that people with ID were 7 times more likely to be the victims of sexual assault.

<https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about>

**“In Their Own Words: People With Intellectual Disabilities Talk About Rape”** by Joseph Shapiro

In this installment of the series, people with ID share their experiences. This includes a 7-minute story as well as individual audio recordings of several people with ID sharing their stories.

<https://www.npr.org/2018/01/20/577064075/in-their-own-words-people-with-intellectual-disabilities-talk-about-rape>

**“Unforgotten: Twenty-Five Years After Willowbrook”** by FilmRise Documentaries

This hour-long documentary provides some background on the horrific injustices that have occurred in state institutions for people with IDD. It is too long to show in full during the workshop, but shorter clips may be shown, or it may be recommended to the participants to watch later if they are interested in learning more. <https://youtu.be/HNLYKW8fCNg>

**“Quality of Life”** by Bruno Kohfield-Galeano

A 30-minute documentary. Start at 11:01 where a mother describes the sexual abuse and subsequent cover-up of Jill while Institutional care. The video describes the change in her behavior before and after the abuse, and before and after Jill receives appropriate care. <https://youtu.be/XWNixFvKiaU?t=661>

**“All Behavior Communication”** by Open Future Learning

A short and somewhat provocative video about “All Behavior is Communication”

<https://youtu.be/iZThnMP8N1I>

**“People with Developmental Disabilities WORK”** by Dan Cleberg

Video showing people with IDD working, highlighting the importance of employment for people with IDD and how this fits in with developmental needs for community connection and contribution. This is a longer video. Starting at 4:20, people with IDD discuss what they value about working.

<https://youtu.be/LCa02lgV0I0?t=260>

The RTC Media YouTube channel features other great videos that may be useful throughout the course.

**“Social Inclusion for people with intellectual and developmental disabilities”** by RTC Media  
An example of the social needs for adults with IDD, including the desire and capability of marriage. This is useful to highlight that adults with IDD have developmental needs associated with adulthood.  
<https://www.youtube.com/watch?v=-dDncNlVzwl>

**“Aging, Retirement, and End of Life for people with intellectual and developmental disabilities”** by RTC Media  
An aging adult with IDD discusses the needs, challenges, and goals he has for himself as he ages.  
[https://youtu.be/yAJO\\_yGa9nA](https://youtu.be/yAJO_yGa9nA)

**“Adults with Developmental Disabilities”** by ShawTVOkanagan  
An example of a program for aging adults with IDD. Highlights the developmental needs of connection, generativity, and meaning making that all people experience as they age, regardless of having an IDD.  
<https://youtu.be/MGIEpswIE5w>

**“Trauma Stewardship”** From the Trauma Stewardship  
A light-hearted look at burnout to play at the beginning of Module 6.  
[https://www.youtube.com/watch?v=tAKPgNZi\\_as](https://www.youtube.com/watch?v=tAKPgNZi_as)

**“What is our Central Purpose in a Culture of Gentleness”** by Creative Options Regina  
This video shares a discussion of Gentle Teaching’s central purpose. This organization posts several other videos about Gentle Teaching that may be beneficial. <https://youtu.be/lwiPBj7ukvc>

**“Gentle Teaching and Trauma Informed Support, a conversation with Karyn Harvey, Ph.D.”** by Creative Options Regina  
An 11-minute video of Dr. Karyn Harvey talking about the overlap between the philosophy and methods of Gentle Teaching and Trauma-Informed Supports, <https://youtu.be/A6CTUUMz7zo>

**“The Power of Gentle Teaching”** by Creative Options Regina  
A video with testimonials from service providers talking about what they value about the Gentle Teaching approach: <https://youtu.be/NpWJkXcmXsl>

**“Trauma Informed Behavior Support Plans with Dr. Karyn Harvey 2021”** by CONNECT-CST North  
Dr. Harvey has a 2-hour presentation on Trauma-Informed Behavioral Planning available on youtube that may be of interest to participants to continue their education: <https://youtu.be/xatOcqtfttl>

**“Reflective Supervision & Consultation: Perspectives from Child Welfare Professionals”** by Center for Advanced Studies in Child Welfare  
A video describing the what reflective supervision is. Although it is in the context of child welfare, the principles apply to working with any traumatized populations.  
<https://www.youtube.com/watch?v=opnneWjli6M>

# ESSENTIAL MESSAGES

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1. Know that there's hope; recovery from traumatic experiences is possible. (Module 1)
2. Recognize that an adult with IDD may have had a traumatic experience(s), which can have profound effects. (Module 1)
3. Recognize an adult'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 an adult'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 an adult regain their sense of safety, value and quality of life. (Module 3)
6. Utilize an IDD- and trauma-informed adult-centered approach to support both the adult and the family. (Module 4)
7. Help parents/caregivers, and other professionals in the adult'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 adult-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

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## **Module 1: Setting the Stage**

- ☐ Define Trauma-Informed Care
- ☐ Realize that people with IDD are at-risk for traumatic experiences.
- ☐ Articulate that recover from traumatic experiences is possible.
- ☐ Establish the important role of parents/caregivers and the support network on the road to recovery.
- ☐ Describe frameworks that will be used to highlight key concepts throughout the training.

## **Module 2: Development, IDD & Trauma**

- ☐ 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 a person's functioning is affected by IDD & subsequent adaptations that must be made.

## **Module 3: Traumatic Stress Responses in People with IDD**

- ☐ Identify the types of events that can cause traumatic stress.
- ☐ Define traumatic stress and trauma-related disorders.
- ☐ Identify how traumatic experiences and their responses affect people with IDD.



# LEARNING OBJECTIVES

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## **Module 4: Well-Being & Resilience**

- ☐ Explore the impact on caregivers of learning about the traumatic experience of the person with IDD they care for.
- ☐ Explain strategies for strengthening protective factors to enhance well-being, resilience, and recovery.
- ☐ Describe frameworks for promoting a healing and protective environment in order to create a safe and meaningful life for adults with IDD.
- ☐ Identify person-centered planning techniques to help adults with IDD realize their hopes and dreams.

## **Module 5: IDD- & Trauma-Informed Services & Treatment**

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

## **Module 6: Provider Self-Care**

- ☐ 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.

# Slide Notes

# Module One

Setting the Stage



## **Say**

Hello Everyone. Welcome to Thriving – Helping Adults with Intellectual and Developmental Disabilities Heal and Thrive Following Trauma.

*Briefly introduce yourself, especially if the audience is unfamiliar to you. You may also choose to do a brief ice-breaker activity depending on the size of the workshop audience.*



This project would not have been made possible without the support and hard work of many people and organizations.

These materials have been adapted with permission from “The Road to Recovery Toolkit: Supporting Children with IDD Who Have Experienced Trauma” developed by the National Center for Child Traumatic Stress, the National Child Traumatic Stress Network, The Hogg Foundation, and a national selection of experts in trauma and IDD.

The toolkit is an excellent resource for providers of children with IDD. If you also work with children with IDD, or if you have separate teams in your organization that support children with IDD, we highly recommend this toolkit as well.

## Advisory Board

Ruth Brown, PhD, Ananda Amstadter, PhD, Michael Southam-Gerow, PhD • Virginia Commonwealth University	Patricia Hagood • Self-Advocate	Colleen Horton, MPAff • Hogg Foundation	Adam Kaul, MD • Regional Education Assessment Crisis Services and Habilitation
Susan Ko, PhD • Science 37	Andrea Konig, PhD • Bon Secours St. Mary's Hospital	Michelle (Shell) Schwartz, MA • SafePlace, TX	

This adaptation was developed by a team of experts, including several people who were responsible for the development of the original Road to Recovery Toolkit.

Funding for this project was made possible by the WITH Foundation which works for Inclusive and Transformative Healthcare for people with disabilities.



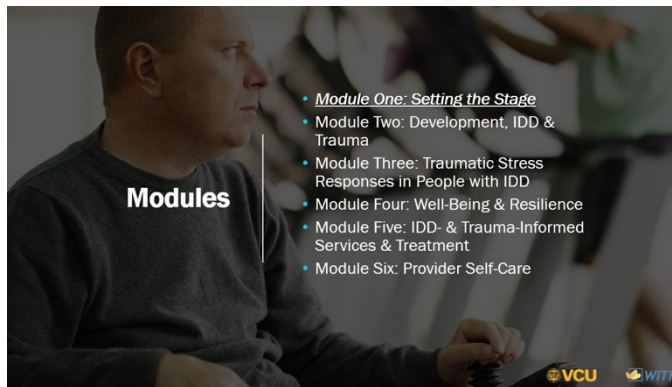
## What's new in this version?

- Focuses on the specific needs of adults with IDD, the contexts in which adults live, the impacts of trauma across the lifespan on adults, and assessment and treatments for adults with IDD
- Updated research findings on prevalence of trauma and stress-related disorders according to the most recent diagnostic manuals used by psychologists (DSM-5 and DM-ID 2)



If you've participated in the Road to Recovery program, there is substantial overlap. Many adults with IDD who experienced trauma in childhood may continue to experience the effects of that trauma into adulthood. Understanding the effects of trauma in childhood is important for understanding the lasting effects of that trauma.

However, we felt that while training in childhood trauma is extremely valuable, it is not sufficient, for supporting adults with IDD who have experienced trauma. This training addresses the continued impact of childhood trauma, plus trauma experienced in adulthood. It addresses the living and occupational environments that adults with IDD experience and how these areas functioning may be impacted by trauma. We also address the assessments and treatments of trauma and stress-related distress that are appropriate for adults with IDD.



This training is broken up into 6 modules. In these modules, you'll learn about the best practices and techniques to help reduce the stress faced by adults with IDD who have also experienced trauma. By understanding development, traumatic stress, and the nuances of working with adults with IDD you'll become more effective at your job, and find more reward in working with the people in your care.

- **Module 1: Setting the Stage**—In this module, you will learn why a Toolkit that addresses the needs of adults with IDD who have had traumatic experiences is important.
- **Module 2: Development, IDD & Trauma**—You'll learn about typical milestones that occur throughout a person's lifespan and how IDD and trauma can detour those milestones and impact their behavior and health throughout the lifespan.
- **Module 3: Traumatic Stress Responses in Adults with IDD**—You'll learn about how traumatic experiences affect development generally, and adults with IDD specifically,
- **Module 4: Well-Being & Resilience**—You'll learn the role of protective factors—such as a secure attachment and a healing/protective environment—in enhancing a person's 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 adults with IDD and their caregiving-system 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 few notes about this training:

The target audience is “providers”, defined broadly: anyone who works with adults with IDD. At times, it may feel like the materials are geared towards direct service providers. Encourage participants to modify how the material presented impacts their role when working with adults with IDD.

The training is conceptualized as an introductory training and designed to lay the foundation for more advanced training in the future (e.g., treatment adaptations for adults 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.

## Self Care

- Step out and take a break.
- Talk to someone you trust.
- Do something relaxing.



## Say

- 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 them.
- You may have friends, or yourself have a child or family-member 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.

## Module one: Learning objectives

### What Will I Learn Today?

- Define Trauma-Informed Care
- Realize that people with IDD are at-risk for traumatic experiences.
- Articulate that recover from traumatic experiences is possible.
- Establish the important role of parents/caregivers and the support network on the road to recovery.
- Describe frameworks that will be used to highlight key concepts throughout the training.



## Module I. Let us start with some learning objectives for what we are going to learn in this module.

- After completing today's training, you should be able to do the following:
  - Define trauma-informed care
  - Realize that people with IDD are at-risk for traumatic experiences. We will talk about the kinds of trauma that are common among people with intellectual disabilities and talk about some of those risk factors.
  - We will emphasize that recovery from traumatic experiences is possible, and it is possible for people with intellectual disabilities.
  - We will discuss the important role of parents and caregivers and their support networks on the road to recovery.
  - Last, we will describe frameworks used to illustrate key concepts throughout the training.

### What does it mean to be “Trauma Informed” ?



Source: [store.samhsa.gov](https://store.samhsa.gov) TIP 57: Trauma-Informed Care in Behavioral Health Services

The Substance Abuse and Mental Health Services Administration identifies the Four R's of Trauma-Informed Care:

- One, Realize the widespread impact of trauma
- Two, Recognize the signs and symptoms of trauma
- Three, Respond by changing behaviors, policies, and services to take trauma into account
- Four, Resist re-traumatization of clients and staff with trauma histories.

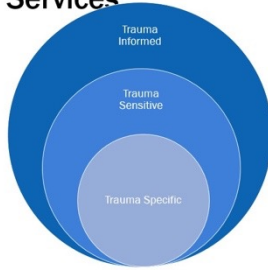
• A trauma-informed organization, for example, would recognize that the adults with IDD in their care may have experienced trauma and that this trauma may be underlying their behavioral actions. The organization would also recognize that physical restraints for someone who has experienced physical or sexual abuse or seclusion or neglect may worsen symptoms. As a result, the organization would change policies regarding restraints and seclusion and develop positive behavioral supports that address the underlying trauma.

• These four Rs are the goals that we hope to achieve through this training. We will not be able to cover interventions in great detail, but we aim to raise awareness of the prevalence and impact of trauma experienced by people with IDD.

Also, support providers in recognizing the signs and symptoms resulting from trauma and provide suggestions for responding to people with IDD who have experienced trauma. Together, this will help us not re-traumatize the people we support but will help end the cycle of trauma, promote growth, and help adults with IDD who have experienced trauma genuinely thrive.

### Three Levels of Trauma Services

- Trauma-Informed
  - Universal intervention
  - Focuses on empowerment, safety, choice
- Trauma-Sensitive
  - Secondary intervention
  - Aims to address trauma through assessment and modification to services
- Trauma-Specific
  - Tertiary intervention
  - Use of evidence-based, or promising, trauma treatments



The Institute on Trauma and Trauma-Informed Care (2019). Trauma-Informed Organizational Change Manual. University of Buffalo School of Social Work. Retrieved from: [www.socialwork.buffalo.edu/ittic](http://www.socialwork.buffalo.edu/ittic)

Being Trauma-Informed is the foundation upon which trauma-specific services are based. Keesler and colleagues identified three levels of trauma-informed services.

**Trauma-informed** reflects the organizational culture and day-to-day practices of an organization. It recognizes that the people whom the organization serves may have experienced trauma, and they recognize the importance of being sensitive to the needs of those people. It is a Universal Precaution that safeguards everyone to avoid re-traumatizing those who have experienced trauma.

**Trauma-sensitive care** focuses on the ways that people within the organization respond to trauma. It involves putting policies and practices in place to support clients and staff in responding to trauma and promoting resilience and wellbeing.

Finally, **Trauma-Specific** services treat trauma through evidence-based or promising treatments, including trauma-focused cognitive behavior therapy or eye movement desensitization reprocessing therapy.

This training will focus primarily on the trauma-informed level, with recommendations for resources to facilitate the adoption of trauma-sensitive and trauma-specific practices.

Keesler, Green, Nochajski (2017). Creating a Trauma-Informed Community Through University-Community Partnerships: An Institute Agenda. *Advances in Social Work*



## Realize

Trauma & IDD: Scope of the Problem



The first R of trauma-informed care is Realize. We will discuss the scope of trauma experienced by people with IDD.

## Trauma & IDD: Scope of the Problem



- Estimates vary regarding the prevalence of traumatic exposure in adults 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 DD** (US Department of Health and Human Services, 2011).
- A study by Crosse et al. in 1993 reported that people with intellectual disabilities were at two times higher the risk of physical and sexual abuse than people without disabilities. Sobsey et al. in 1995 found that individuals with intellectual disabilities were four times more likely to be victims of crime than those without disabilities.
- People with DD were over twice as likely to experience *emotional neglect* (4.7/1000) than people without disabilities.
- There is evidence that certain behaviors are a mediating factor for maltreatment in this population. Externalizing behavior, which has a greater incidence among people 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 an increased risk of *sexual abuse* (Turner et al., 2011).
- *Domestic violence* is estimated to be almost three times more likely in families of people with DD (Sullivan, 2006).
- People with IDD are four times 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).
- Be sensitive to "blaming" caregivers when indicating a higher likelihood that people with IDD will be physically & sexually abused.

## Trauma & IDD: Scope of the Problem



Cont.

### Say

- People with IDD are subjected to traumatizing physical restraint and seclusion that are rarely encountered by peers who are non-disabled (Sullivan, 2006).
- People with IDD had significantly higher rates of emotional neglect and severe injury compared to peers who are non-disabled (Sedlak et al., 2010)
- *Psychological distress secondary to medical procedures* is another potentially traumatizing experience that is more common to people with DD than to their typically developing peers. They may have chronic medical problems that necessitate surgeries and other invasive procedures.

### **Additional Stats**

- *Serious harm* was estimated to occur at 8.8 per 1000 for people with a confirmed diagnosis of DD compared to 5.8 per 1,000 rates for their non-disabled peers
- People 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).
- Disability contributes to the risk of abuse, however, people with intellectual disabilities, communication disorders, behavioral disorders, and multiple disabilities have the highest risk of abuse and neglect (Sullivan & Knutsen, 2000).
- People with IDD had significantly higher rates of *emotional neglect* and *severe injury* compared to their non-disabled peers (Sedlak et al., 2010).
- People with IDD have a higher rate of abuse than people without disabilities (Ryan, 1994); one study found the likelihood was 1.68 times higher (Child Welfare Information Gateway, 2012)
- When people with IDD live in a household lacking structure and characterized by chaos and threats, their ability to “track” along “typical” developmental and emotional strands can be compromised.
- An additional challenge is that people with IDD may start below average or “off” charts that track developmental milestones, making it challenging to assess how a traumatic experience may be affecting their functioning (using the chart) compared to typically developing peers.
- The functional and behavioral manifestations of traumatic stressors can place young people with IDD at even further risk of becoming *victims of additional trauma – physical, emotional, cognitive, or combined*.

## NPR Special Series: Abused and Betrayed. The Sexual Assault Epidemic No One Talks About



<https://www.npr.org/series/575502633/abused-and-betrayed>

VCU WITH

### Facilitator Notes

#### Say

A year-long investigation and analysis of unpublished Department of Justice records found that people with intellectual disability experience sexual abuse at a rate of more than **7 TIMES that of people without a disability.**

In this series, which aired in January 2018, journalist Joseph Shapiro interviews sexual assault survivors and talks about the challenges people with IDD have faced in obtaining legal justice. In June 2018, NPR reported that many states have started proposing legislation to do something about this epidemic.

There is still much work to be done. When people 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 may also stem from increased risk of early puberty, multiple caregivers providing intimate care, and educational and communication barriers.

<https://www.npr.org/series/575502633/abused-and-betrayed>

#### Optional Audio

**Personal accounts of rape experienced by people with IDD. These stories are explicit and can very difficult to listen to.**

**Full story 7:49.**

**To embed:**

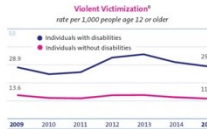
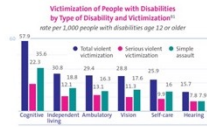
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```

Individual clips also available <https://www.npr.org/2018/01/20/577064075/in-their-own-words-people-with-intellectual-disabilities-talk-about-rape>

## Trauma & IDD: Scope of the Problem

- “... those numbers from household surveys don't include people living in institutions — where, Harrell said, research shows people are even more vulnerable to assault. Also not counted are the 373,000 people living in group homes.”

The Sexual Assault Epidemic No One Talks About: NPR.  
<https://www.npr.org/2018/11/18/2070240902/the-sexual-assault-epidemic-no-one-talks-about>



VCU WITH

## Facilitator Notes For Your Eyes Only

- There is an animation on this slide. You will have to initiate the animation for the slide content. Please be aware of when you will need to click the remote or press the space bar.

### Say

The Bureau of Justice Statistics National Crime Victimization Survey has consistently found that people with disabilities experience violent victimization at a rate of 2.5 times higher than people without disabilities.

The groups with the highest rate of victimization include people with cognitive and independent living disabilities.

Why is this rate lower than some of these other studies have found? For one, researchers have found that people with IDD may be more likely to underreport victimization compared to non-disabled peers for fear of coercion or shame (Reiter et al., 2007).

**Also, click the remote or press the space bar:** national surveys are often called “household” surveys. They do not include people living in institutions or group homes where people with IDD are most vulnerable to abuse.

## History of Institutional Care

- Willowbrook State School and others
- Overcrowding
- Abuse
- Neglect
- Unethical medical experimentation



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Unfortunately, the history of people with IDD living in institutional care and group homes is a dark one, and relatively recently.

Willowbrook State School was one of the highest profile institutions, but facilities like this existed across the country.

Of the many atrocities committed at Willowbrook was hepatitis vaccine experimentation that involved purposely feeding children live hepatitis virus from the stool of other infected children. A recent 2020 New York Times investigation found that many of the former residents of Willowbrook, now in their 50s and 60s, continued to experience abuse and neglect in smaller group homes.

For more about Willowbrook see "Unforgotten: Twenty-Five Years After Willowbrook" <https://youtu.be/HNLYKW8fCNg>

### Optional Videos:

Quality of Life Documentary: start at 11:01, A mother and sister describes the sexual abuse and subsequent cover-up of Jill while Institutional care. The video describes the change in her behavior before and after the abuse, and before and after Jill receives appropriate care. <https://youtu.be/XWNixFvKiaU?t=661>

## Trauma & IDD: Scope of the Problem

- Study in the United Kingdom found that approximately 1,400 reports of sexual abuse committed against people with intellectual disability are reported annually
  - Only 6% reach the court
  - Only 1% result in conviction



This Study by Unknown Author is licensed under CC BY-NC-ND



### Facilitator Notes

#### Say

This is not just a problem in the United States. A recent study in the United Kingdom found that rates of sexual abuse of children and adults with intellectual disabilities were higher than people without disabilities. Researchers' also found that the likelihood of people with IDD receiving protection under the law was extremely low, with only 6% of cases going to court and only 1% resulting in a conviction.

Byrne, G. (2017). Prevalence and psychological sequelae of sexual abuse among individuals with an intellectual disability: A review of the recent literature. *Journal of Intellectual Disabilities*, 1744629517698844. <https://doi.org/10.1177/1744629517698844>

## Trauma & IDD: Barriers to Recovery

- High rates of out-of-home placements
- Providers often feel insufficiently equipped to support people with IDD and trauma histories.
- Treatments for people with IDD often focus on behavioral compliance.
- Traumatic stress can lead to changes in learning, behavior & physiology—may place people at risk for further trauma.



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### Facilitator Notes :

#### Say

- We know that adults with IDD are at-risk for trauma. We also know that they are more likely to suffer from ongoing adverse effects of that trauma due to treatment barriers. For example,
- High rates of out-of-home placements
- Resulting in difficulty gathering a detailed trauma history
- Limited peers to peer support networks that could provide additional sources of support for the traumatized person
- Multiple disrupted placements throughout their childhood and adulthood, which can be traumatic in itself.
- Providers often feel insufficiently equipped to support people with IDD with trauma histories. For example,
- Adults with IDD are perceived as challenging to work with and are misunderstood, leaving clinicians uncertain about how to move forward in treatment.
- Clinicians may fear, lack interest, or resist acquiring cultural competency with this population due to disability stigma and lack of awareness of the problem.
- A lack of trauma-informed service providers: they fear what they do not know, and they focus on what is wrong with you vs. what happened to you.
- Treatments for adults with IDD often focus on behavioral compliance. For example,
- Traditional evidence-based trauma interventions often exclude this population
- The default is to utilize a behavioral focus due to communication limitations
- Adults with IDD exhibiting challenging behaviors often do not receive state-of-the-art mental health treatment; instead, the focus is on managing their behavior with compliance as the primary goal.
- Cultures of care in residential and community or family settings have historically been similar to reducing maladaptive behaviors by focusing solely on consequences and replacing undesirable behavior with behaviors deemed “appropriate.”
- It is 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 experience).
- 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 reduced. •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 adults with IDD at even further risk of becoming a *victim to further trauma* – physical, emotional, cognitive, or some combination.





## Trauma & IDD: Barriers to Recovery

- People with IDD are under-identified & under-served & often lack trauma-informed services when required.
  - Diagnostic overshadowing
  - Inadequate trauma screening & assessment tools
  - Assumptions made about (in)ability to engage in treatment.
- Quality integrated care and intensive case management needed for successful trauma treatment is resource intensive for this population.
  - Fragmented services
  - Low reimbursement rates



### Say

- People with IDD are under-identified and served and lack trauma-informed services. The barriers to accessing the care they need include:
  - “Diagnostic overshadowing” is a 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 accustomed to seeing the individual through the lens of the disability can misinterpret behaviors that are symptomatic of mental illness, distress, or past trauma.
  - In attributing challenging behaviors solely to the disability, opportunities for recovery are missed resulting 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 recover from traumatic stress spontaneously, so the need for adequately adapted trauma treatment is evident.
  - Inadequate trauma screening & assessment tools. While many trauma screening and assessment tools exist, they may need to be adapted to be effectively used with adults with IDD. This will be addressed more in Module 5.
  - Assumptions made about an inability to engage in treatment.
  - Professionals often make incorrect assumptions about adults with IDD and their capacity to engage in commonly-used therapeutic techniques and strategies such as cognitive-behavioral therapy.
  - It is essential to provide information to treatment providers about assessing a person’s abilities, strengths, and needs.



## Trauma & IDD: Barriers to Recovery

- People with IDD are under-identified & under-served & often lack trauma-informed services when required.
  - Diagnostic overshadowing
  - Inadequate trauma screening & assessment tools
  - Assumptions made about (in)ability to engage in treatment.
- Quality integrated care and intensive case management needed for successful trauma treatment is resource intensive for this population.
  - Fragmented services
  - Low reimbursement rates



Cont.

- Even highly 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 opportunities for building capacity to serve adults with IDD who have experienced trauma and 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 who serve the IDD population, high turnover rates are due to providers' secondary traumatic stress and burnout. Also, high levels of supervision and intensive case management are usually required
- Authorization denials require advocacy and complicated appeal taking considerable amounts of time, all of which is non-billable.
- Diagnosis, treatment planning, and crisis prevention require 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 include:  
Availability & quality of services varies across regions, states & communities depending on funding and services structure.
- Services often occur in silos.
- Adults may have a different care coordinator and different treatment plan in several systems, without any providers talking with each other.
- People may be excluded from services (like mental health or trauma treatment) explicitly because of an intellectual disability.
- Low reimbursement rates result in minimal access to highly-trained providers.
- Also, due to *low reimbursement rates for services*, providers who run group homes, day habilitation programs may employ service providers with limited education, training, or skills to provide care for people with ID/DD.

"We went to them and they had **no idea** how to help us."



VCU WITH

### **Say**

- Anyone ever had an adult with IDD say this to them? *[If someone raises their hand or is shaking their head, ask them how they responded.]*

The needed expertise to help people with IDD is not found in many communities, even less so when trauma is involved.

## Myths about People with IDD

- People with IDD cannot engage in treatment
- Standard mental health treatment is ineffective for people with IDD
- Behavior modification is the only option
- People with intellectual disabilities do not experience trauma
- Working with this population requires significant specialized training
- A challenging behavior is explained by an intellectual disability
- People with IDD are protected from trauma because of their mental age (i.e., babies); they do not remember
- IQ scores tell you everything you need to know about a person

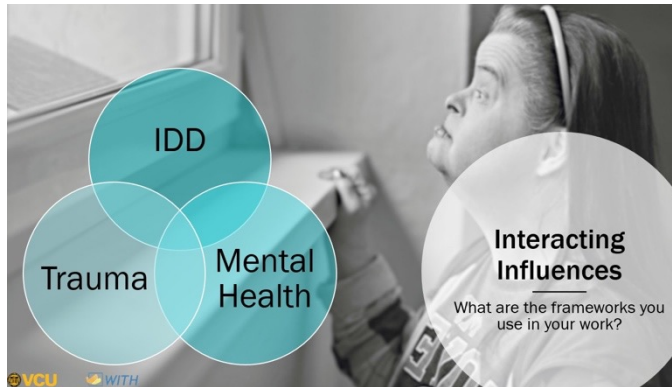


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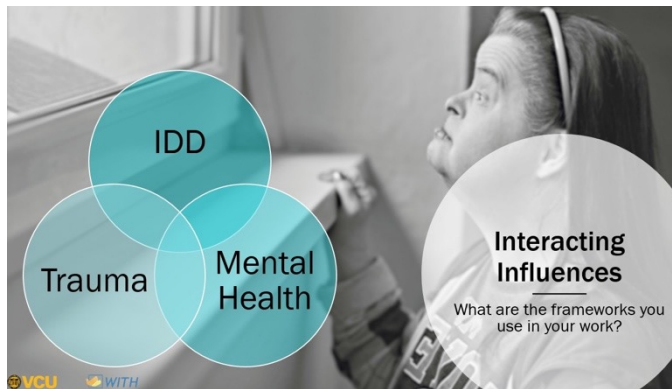
## Say

- It is essential to be aware of your biases and perceptions regarding people with IDD. For example,
  - People with IDD cannot engage in treatment
  - Standard mental health treatment is ineffective for people with IDD
  - We 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
  - People with intellectual disabilities do not experience trauma
  - We know that this is not 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 people 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.
  - Youth with IDD are protected from trauma because of their mental age (i.e., babies); they do not remember
  - Recognize that IQ scores do not indicate a person's adaptive functioning regarding traumatic experiences and responses or the emotional state.
- 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.]*
- **(Click the remote or press the space bar).** These statements are not factual but are commonly perceived to contribute to adults with IDD not receiving the care and treatment they need. Through the course of this training, we will disprove these myths.



### **For Your Eyes Only**

- *There is an animation on this slide. You will have to initiate the animation for the slide content. Please be aware of when you will need to click the remote or press the space bar.*
- *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.*
- **Optional Exercise:** *Use chart paper or whiteboard to draw the three circles. Go around the room and ask participants to introduce themselves and identify what their primary framework/training/setting is and place a dot in that section. Do they work primarily in an IDD setting (e.g. day program, residential setting, etc.)? Mental health setting (e.g. community mental health clinic, private practice, psychiatric hospital), Trauma focused setting (e.g. emergency room, crisis support, adult protective services). Some people will work at the intersections (e.g., a community mental health clinic that specializes in trauma recovery; a crisis support program for people with IDD). There is a tendency as you go around the room for people to “pick up on” the goal of the activity to highlight that these worlds intersect and want to place themselves in the center.*



Cont.

### Say

- **click the remote or press the space bar:** Mental health and trauma treatment providers have various 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.

- **click the remote or press the space bar:** Providers in the IDD field tend to use frameworks that focus on creating adaptive environments to increase opportunities and build skills. Recovery is not necessarily a familiar term in the IDD field. We want to change that, and incorporate it into our language.

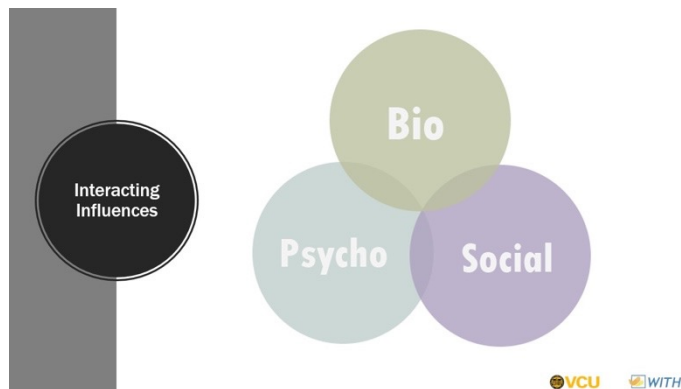
- This Toolkit seeks to do both by focusing on creating adaptive environments to increase opportunities (e.g., support health and safety) *and* recovery (build people back up, help them overcome traumatic experiences, feel good about themselves again, and thrive in daily experiences).

- How are these frameworks similar or different? What roles do participants have? *[Allow 7 minutes for the participants to discuss this question at their tables. Once the time has elapsed, please have each participant introduce themselves and say something BRIEF about the framework they use.]*

- A note about definitions:

- **IDD:** the Toolkit is focusing on intellectual and developmental disabilities broadly. We recognized that there is a wide range of functioning within IDD, 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 explore further when working with people with IDD. We will further define IDD in Module 2.

- The Toolkit frequently refers to using **“trauma-informed” supports and services**, referring to recognition and response to traumatic experiences. For example, a trauma-informed approach would consider the question, “what happened to you?” instead of “what is wrong with you?” Traumatic stress and responses will be defined explicitly in Module 3.



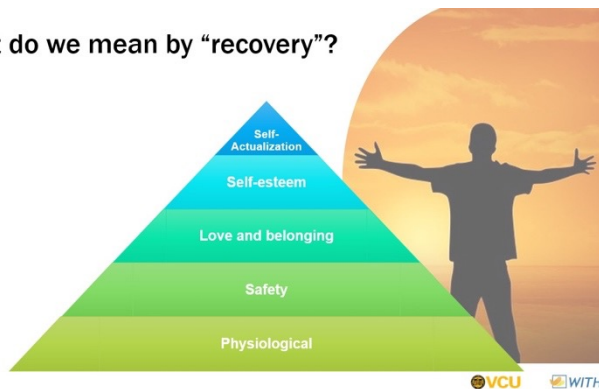
## Facilitator Notes

### Say

There are many frameworks for understanding the traumatic stress response of adults with IDD. These frameworks arise out of multiple disciplines that interact with people with IDD, and there are often diverse frameworks within a discipline. This Toolkit will not describe all the possible frameworks in great detail, but many of them can be described by the BioPsychoSocial framework. This framework demonstrates that a person's current state is the product of biological influences (such as physical disabilities, genetic difference, neurological difference), psychological influences (such as previous traumas or stressors, coping abilities, cognitive abilities), and social influences (such as formal and informal support networks, culture, and public policy).

We will talk about a few frameworks as we progress through the course.

What do we mean by “recovery”?



## Facilitator Notes

### Say

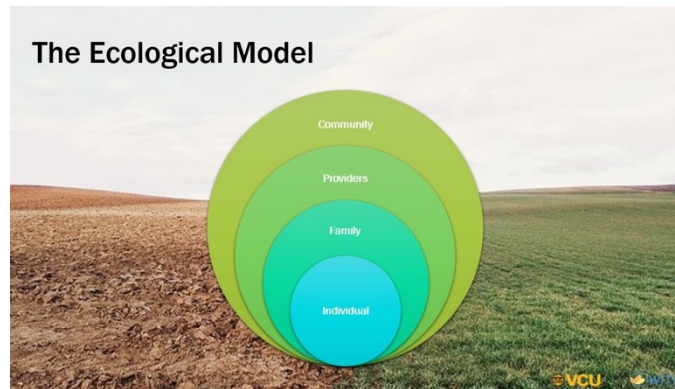
- Maslow’s hierarchy of needs is a helpful framework for considering what all people need for healthy development.

- People with IDD are no different

We tend to focus on people with IDD Physiological and Safety needs.

However, we cannot stop at safety. It is also essential to focus on supporting adults with IDD in developing loving relationships, building self-esteem, and helping them realize their potential by providing the foundation for meaningful relationships, self-esteem, and self-actualization.





### **Say**

- The ecological systems theory of development, conceptualized by Urie Bronfenbrenner, emphasizes that many societal and environmental factors influence development.
- For this training, the ecological model helps us think about three primary systems that we will focus on throughout this training: the person, family (defined broadly), and service providers.

## The Risk & Protective Factors Model



### For Your Eyes Only

- There are several animations on this slide. You will have to initiate the animation for the slide content. Please be aware of when you will need to click the remote or press the space bar.

### Say

• A fourth framework that will serve as a foundation in our discussion is the risk and 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 it as a brick wall. (Click the remote or press the space bar). Bricks the support people and families include:

• (Click the remote or press the space bar). Attachment with a primary caregiver

• Self-esteem/self-efficacy

• Adaptive coping skills

• Strong social support network

• Mentors

• Supportive community environment

• (Click the remote or press the space bar). However, rain erodes the mortar and weakens the brick wall. These are risk factors. They diminish health and make it more difficult to reach one's full potential.

For people 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.

• Preexisting Emotional problems

• Behavioral/genetic/medical co-morbidities

• Cognitive deficits

• Communication challenges

• Impaired problem-solving

• Lack of social supports

• Higher levels of poverty & social isolation related to societal attitudes about disability

• **And of course, Traumatic experiences**



### Say

- (Click the remote or press the space bar). Extending our metaphor, traumatic experiences may further weaken or break down protective factors.



**You Can Do This Work**

- Don't let fear and apprehension about IDD be a barrier for you.
- An effective provider:
  - Knows recovery is possible.
  - Uses language and a means of communication that is understandable and appropriate for each person.
  - Knows the person with IDD and their caregivers have just as much to teach you as you have to teach them.

VCU WITH

### **Say**

- There is a misconception among providers that working with people with an IDD diagnosis and trauma is entirely different from their non-disabled peers. This is not true.
- Working with people with IDD is much more like working with typically developing people than it is different.
- Treatments have been adapted for people with IDD, and these adaptations are more similar than different.

## Activity – Making the Connection



*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 person with IDD who has experienced trauma and to keep that person in mind over the course of the next two days. Participants should think about that person and consider how the information they learn in the training could help them help that person.*

### **Say**

Pull out your handout titled, **Making the Connection: Why am I doing this work?** This worksheet asks you to think about a person with IDD who has experienced trauma—think about a person who connects you to this work. Perhaps this is a person in your classroom, on your clinic, or your niece or friend. Perhaps this person is the reason you started doing this work. Perhaps this person is the reason you want to know more about IDD and trauma. As we go through the content of the Toolkit, I ask that you keep this person in your mind, and think about how the information you are learning could apply to that person. If you can't identify a person to think about, you can choose one of the case vignettes in your **Participant Manual** to focus on.

# MAKING THE CONNECTION: WHY AM I DOING THIS WORK?

---

Think about what brought you to this training today. Is the reason professional? Personal? Is there a person with intellectual and developmental disability, in particular, whom you are thinking about?

- What is it that connects you to this work?

- What would you like to know?

### Essential Messages of Working with People with IDD who have Experienced Trauma

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



### Facilitator Notes For Your Eyes Only

- There are several animations on this slide. You will have to initiate the animation for the slide content. Please be aware of when you will need to click the remote or press the space bar.*

### Say

- 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. (Click the remote or press the space bar). Know that there's hope; recovery from traumatic experiences is possible.
- 2. (Click the remote or press the space bar). Recognize that a person with IDD may have had a traumatic experience(s), which can have profound effects.



### What Can a Provider Do?

- Create a learning climate/culture—honor the person's, caregiver's and provider's experience.
- Identify any fears or biases I have about working with people with IDD who have had traumatic experiences.
- Identify ways to increase my knowledge & skills



### **Say**

- At the end of each module, we will end with this question, "What Can a Provider Do?" to give you some time to identify specific strategies that you would like to integrate into your practice.
- Here are some things that you as a provider can do to address the concepts that we just discussed in Module I. Let us take a few minutes to think about what you can do specifically in your role and your organization to address any one of these points.



## Activity – Action Planning

Essential Messages 1 & 2



### Facilitator Notes For Your Eyes Only

*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.*

### Say

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.]*

# ACTION PLANNING

## ESSENTIAL MESSAGES 1 & 2

---

Think about the person you identified at the end of Module 1 that connects you to this work. What can help that person and other adults with IDD who have experienced trauma? (Put an “X” in up to 3 boxes next to the ideas you think you would MOST like to emphasize in your daily practice.)

### 1

#### ESSENTIAL MESSAGE 1

Know that there’s hope; recovery from traumatic experiences is possible.

- ☐ Over the next 3 months, I will identify my personal fears and/or biases of working with adults with IDD. I will begin to utilize the resources described in this Toolkit to help me to address those fears with knowledge and skills training.
- ☐ Over the next 3 months, I will read at least 2 articles online, or in peer-reviewed journals that describe the prevalence of trauma among adults with IDD.
- ☐ Over the next 3 months, I will articulate that recovery from traumatic experiences for adults with IDD is possible, to at least 3 adults with IDD and their caregivers.

### 2

#### ESSENTIAL MESSAGE 2

Recognize that adults with IDD may have traumatic experiences, which can have profound effects.

- ☐ Over the next 3 months, I will identify 3 ways in which traumatic experiences are impacting the **quality of life** for at least three adults with IDD. I will review these areas each time I meet with them.
- ☐ Over the next 3 months, I will identify **concerns and hopes**, of caregivers of 3 adults with IDD who have experienced trauma. I will review these areas each time I meet with them.
- ☐ (**Write my own.**) Over the next 3 months, I will...



## Recovery is Possible

Most importantly, provide HOPE that people with IDD can recover from trauma.

- Help (re-)establish a sense of safety
- Listen, hear & validate what happened to them
- Support their caregiving system
- Provide trauma-informed support & services
- Provide trauma-informed treatment



## **For Your Eyes Only**

- *There is animation on this slide. You will have to initiate the animation for the slide content.*
- Please be aware of when you will need to click the remote or press the space bar.*

## **Say**

- When working with people with IDD and their caregivers, provide hope that people with IDD do recover from trauma. Here are a few things that you can do as a provider.

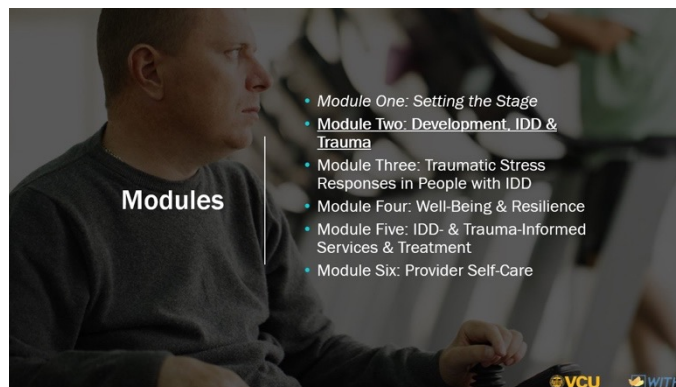
• (Click the remote or press the space bar)

Help establish or re-establish a sense of safety

- Listen, hear, and validate what happened to them
- Support their caregiving system
- Provide trauma-informed support & services
- Provide (or refer to) trauma-informed treatment

# Module Two

Development, IDD, and Trauma



## Facilitator Notes

### Say

- In Module One, we discussed why a Toolkit that addresses the needs of people with IDD who have had traumatic experiences is essential.
- In Module Two, you will learn about typical milestones throughout a person's development and how IDD and traumatic experiences can disrupt those milestones.

**Module Two: Learning Objectives**  
**What Will I Learn Today?**

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



## **Facilitator Notes**

### **Say**

After completing Module Two, you should be able to do the following:

1. Define IDD and various types of disabilities.
2. Discuss developmental tasks across typical development.
3. Describe how IDD and traumatic experiences may disrupt typical development.
4. Identify the areas in which a person's functioning is affected by IDD and implementing adaptations



## What is Development?

Development is the process of change by which people become able to handle even more complex levels of moving, thinking, feeling and relating to others.

### **Facilitator Notes For Your Eyes Only**

- Read the slide.*



## Types of Development

---

- Language
- Motor
- Cognitive
- Social/Emotional
- Adaptive

*How does a person develop to his/her full potential?*



### Note:

*The next several slides provide background on the different domains of development and types of developmental disabilities. This may be helpful for training clinicians who do not routinely provide services for people with IDD. If your audience is experienced with IDD, you may consider skipping or shortening the time spent on this section.*

## Facilitator Notes

### Say

•In Module Two, we will focus on five specific domains of development: language, motor, cognitive, social and emotional, and adaptive skills.

As a provider, being aware of these domains of development helps us consider how we can support a person develop to his or her full potential. We will consider each of these areas of development and then discuss how IDD and trauma might interact with development.



## Development

### Language development /Communication

#### Expressive language

- Communication using sounds, gestures, or words.

#### Receptive language development

- Recognition of sounds & understanding of spoken words & directions.

#### Pragmatic communication:

- Nonverbal & social communication



### The first domain is **Language Development**

- Expressive: how well a person communicates using sounds, gestures, or words
- Receptive: how well a person recognizes sounds and how much they understand spoken words and directions
- Pragmatic communication includes nonverbal and social communication.

## Development

### Motor Development

#### Gross Motor

- Large muscle groups
- Walking, running

#### Fine motor development

- Precision movements
- Tying shoes, writing



VCU WITH

**Motor Development** refers to how the body increases in skill and performance. •Gross motor development: how well a person can move his or her body; the development of our large muscle groups (e.g., walking, running, skipping). •Fine motor development: how well a person 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)

## Development

### Cognitive Development

- Attention
- Memory
- Spatial Ordering
- Sequential Ordering
- Problem Solving
- Social Thinking



VCU WITH

**Cognitive development** is learning the skills of understanding, memory, concentration, and learning to communication with family, friends, and community.

•In the early years, cognitive development is focused on orienting, attention, and fundamental problem-solving. At school age, cognitive development focuses on functions related to neurodevelopment and intelligence.

•**Neurodevelopment** includes eight 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 and oro-motor, sucking, chewing, speech articulation).
7. Higher Thinking (problem-solving, critical thinking, rules, creativity)
8. Social Thinking

## Development

### Social/Emotional Development

- Self identity
- Relationships
- Social norms
- Sensory preferences and sensitivities
- Emotion regulation



VCU WITH

**Social/Emotional** is the development of a person's identity, self-image, relationships, behavior patterns, and learning the skills to live in society as a community member.

Social/emotional development includes behavioral development.

- Sensory development is included in Social-Emotional development, and sensory preferences and sensitivities are important throughout the lifespan.
- The ability to regulate feelings and behavior, emotion regulation, is a central part of social-emotional development.

## Development

### Adaptive functioning

- ability to adjust to various demands of normal daily living

### Self-Care

- activities such as eating, toileting, bathing

### Community

- interest in activities outside the home

### Home Living

- taking care of/assisting with household tasks & taking care of personal possessions

### Health & Safety

- knowledge of basic health activities & physical dangers



**Adaptive** functioning is the ability to adapt to various demands of daily living.

- Self-care: activities such as eating, toileting, and bathing
- Community: leisure activities, interest in activities outside the home, and relationships with others.
- 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, taking care when around a hot stove)

All domains of development that we discuss, such as motor skills, social communication skills, and self-regulation skills, are related to adaptive functioning and how a person can independently or with support negotiate their lives in the world.

### Federal Definition of Intellectual and Development Disabilities

- Impacts available services for people & families
- Emphasizes functional limitations in adaptive behaviors:
  - Self-Care
  - Receptive & Expressive Language
  - Learning
  - Mobility
- Self-Direction
- Capacity for Independent Living
- Economic Self-Sufficiency
- Impacts how or what parts of the system(s) families need to know how to navigate



### Facilitator Notes

#### **Say**

- Knowing the federal definition of IDD is important because it impacts the available services for people with IDD and their families. Clinicians and families need to know how to navigate the system.
- The definition emphasizes functional limitations in adaptive behaviors (which manifest before the age of 22) or understanding of the impact of the disability on functioning.
- Review of areas of functional limitations can be supported by accommodations and skill-building.
- See the Supplemental Materials Section for the full definition.

## Traits vs. Skills

- Traits
  - A distinguishing characteristic or quality, especially of one's personal nature.
  - An inherited feature or characteristic.
- Skills
  - Proficiency, facility, or dexterity that is acquired or developed through training or experience.
  - A developed talent or ability.



VCU WITH

## Facilitator Notes

### Say

- It is also important to understand the distinction between traits and skills, particularly when discussing IDD. While people with IDD may have genetic conditions and specific aspects of their development that cannot be changed (i.e., traits), skills can be learned. Too often, people with IDD, especially those with severe to profound ID, are perceived as having fixed learning abilities, when in fact, they are life-long learners and capable of developing skills throughout their life; this includes resiliency skills.



### **Say**

• There are many different types of disability. Although this Toolkit will not cover all disabilities, we will review different disabilities to recognize a range of issues that people with IDD face. Additionally, there are different assessment strategies and strategies for accommodation and 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)

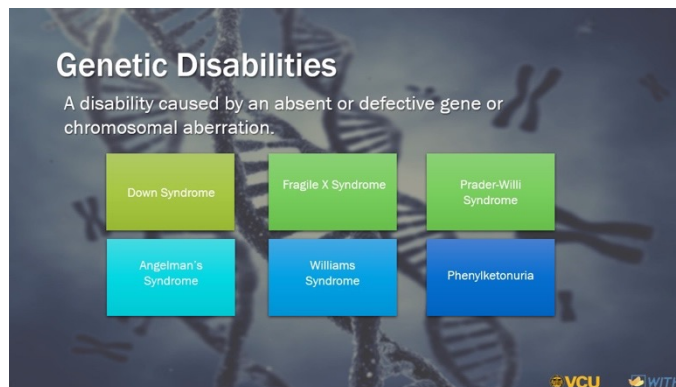
• It is helpful to use a biopsychosocial model when thinking about the categorization of disabilities: biological, psychological (thoughts, emotions, behaviors), and social (socio-economical, socio-environmental, cultural) factors, all play a significant role in human functioning in the context of disabilities. 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 do not “cleanly” fit into just one category. However, it gives us a place to start with thinking about different types of disabilities for this training.

• The Supplemental Materials Section has more information on specific types of disability, with links to videos and additional resources.

• Let us briefly take a deeper look at each of these domains of disability.





## Facilitator Notes

### For Your Eyes Only

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### Say

• A genetic disability is a disability caused by an absent or defective gene or chromosomal aberration. Examples include:

• (Click the remote or press the space bar). **Down Syndrome.** Down Syndrome (trisomy 21) is caused by having three copies of the 21st chromosome instead of the usual two copies. It is a common cause of Intellectual Disability (ID) in people. Co-occurring medical symptoms (such as congenital heart defects, respiratory and hearing problems), and various mental health issues (including anxiety and ADHD) may be seen.

• **Fragile X Syndrome.** Fragile X Syndrome is another common inherited cause of ID in people. Many people with Fragile X also have autism. A mutation on the X chromosome causes it. Boys, who have only one X chromosome, are usually more affected than girls.

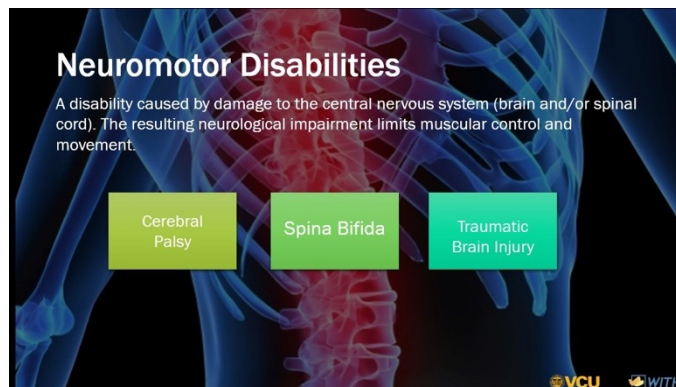
• **Prader-Willi Syndrome.** Prader-Willi Syndrome (PWS) is a non-inherited genetic disorder usually characterized by mild ID, overeating and obesity, and obsessive-compulsive behavior.

• **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.

• **Phenylketonuria.** PKU is an inherited metabolic disorder that can cause severe ID if the metabolic problem is not addressed adequately through a very restrictive diet.

• Note that a parent inherits not all genetic disabilities. For example, Down Syndrome is a non-inherited disability caused by an error in how the chromosomes segregate, causing a person to inherit an extra chromosome 21.



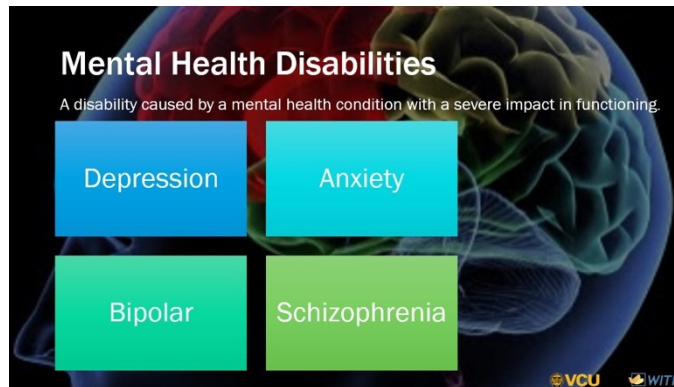
## Facilitator Notes

### For Your Eyes Only

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### Say

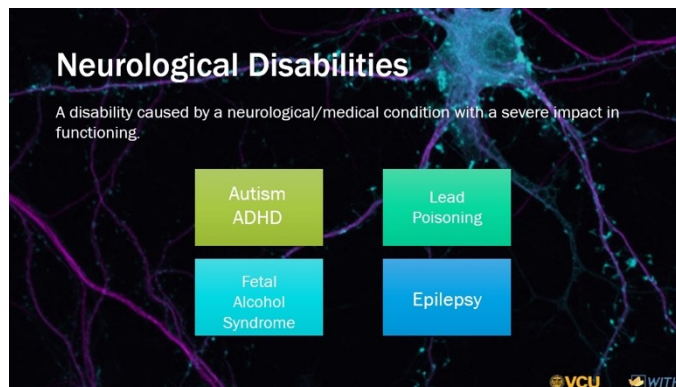
- A neuromotor disability is a disability caused by damage to the central nervous system (the brain and the spinal cord). The resulting neurological impairment limits muscular control and movement. Examples include:
  - (Click the remote or press the space bar). **Cerebral Palsy** is a condition marked by impaired muscle coordination (spastic paralysis) and other disabilities, typically caused by damage to the brain before or at birth. People 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.
  - (Click the remote or press the space bar). **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.
  - (Click the remote or press the space bar). **Traumatic Brain Injury (TBI)** is 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.



## Facilitator Notes

### Say

- A mental health disability is a disability caused by a mental health condition with a severe impact in functioning, and may include severe depression, anxiety disorders such as obsessive compulsive disorder, panic disorder, generalized anxiety, or social anxiety, bipolar disorder, sometimes called Manic Depression, and schizophrenia, among others.
- 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 and 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.
- It is important to understand how diagnostic labels can be 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.



## Facilitator Notes

### For Your Eyes Only

- *There is animation on this slide. You will have to initiate the animation for the slide content. Please be aware of when you will need to click the remote or press the space bar.*

### Say

• This domain is quite broad and includes neurological and medical conditions. However, not every person with a medical issue has a disability. For example, many people have epilepsy they control with medication, and it does not impact their functioning or ability to participate in most, if not all, activities as their peers. For some people, though, medical conditions severely impact functioning and are thus considered a disability. Examples include:

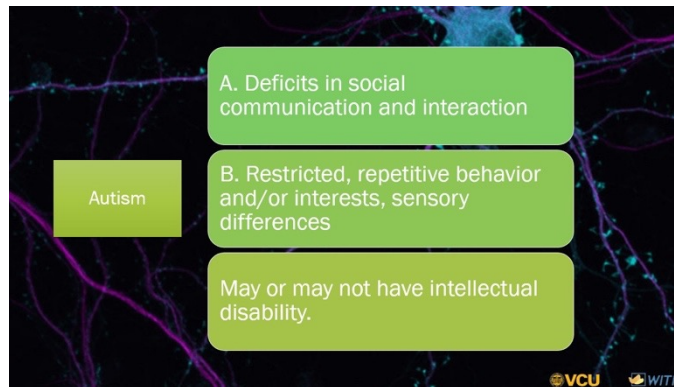
• (Click the remote or press the space bar). Autism is not a mental health condition, although Autism Spectrum Disorder is a diagnosis in DSM-V. It is a disability; people with autism do not "recover." We teach them how to manage the world they live in. Additionally, autism is often characterized by ID, sensory conditions, language deficits, and inappropriate social behaviors. Again, it is important to note how diagnostic labels can be helpful and harmful, as discussed in the last slide.

• ADHD is increasingly recognized as a condition due to neurodevelopment immaturity and a developmental delay, a neurological condition. However, it is still considered a mental health diagnosis and is reimbursed as such.

• (Click the remote or press the space bar). 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.

• (Click the remote or press the space bar). Lead poisoning occurs when lead builds up in the body, often over months or years. Even small amounts of lead can cause serious health problems. People 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.



### **Say**

We will focus on Autism Spectrum Disorder (ASD) with a prevalence rate of 1%. Our understanding of ASD has changed substantially over the years.

ASD is characterized by two main diagnostic features: A) deficits in social communication and interaction and B) restricted or repetitive behavior or interests. Sensory differences also fall within this category.

People with ASD may or may not have an intellectual disability. About a third of people with ASD also have ID.

ASD used to be three separate disorders: Autism (when the person also had ID), Asperger's syndrome or High Functioning Autism; when the person did not have ID), and Pervasive developmental disorder when the person has significant symptoms of Autism, but not all symptoms). They are all under the Autism Spectrum Disorder Umbrella and we specify the severity based on the level of support the person needs (Requiring Support, Requiring Substantial Support, and Requiring Very Substantial Support).



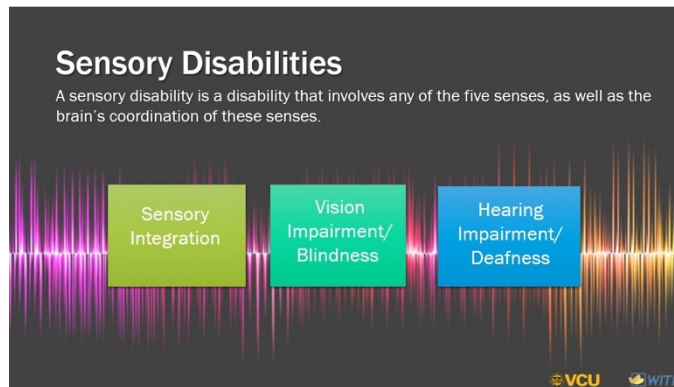
## Facilitator Notes

### For Your Eyes Only

- *There are several animations on this slide. You will have to initiate the animations for the slide content. Please be aware of when you will need to click the remote or press the space bar.*

### Say

- Intellectual disability includes significant intellectual functioning limitations and adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.
- *(Click the remote or press the space bar)* 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 of up to 75 might also indicate a limitation if an individual has significant challenges in his/her adaptive functioning.
- *(Click the remote or press the space bar)* Adaptive behavior is the collection of conceptual, social, and practical skills 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 the rules/obey laws and avoid being victimized.
- Practical skills—activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, and telephone use.
- *Source: American Association on Intellectual and Developmental Disabilities*



## Facilitator Notes

### For Your Eyes Only

- *There is animation on this slide. You will have to initiate the animation for the slide content. Please be aware of when you will need to click the remote or press the space bar.*

### Say

- 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.
- (Click the remote or press the space bar.) 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 appropriately and automatically. 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
- (Click the remote or press the space bar.) Vision impairment/blindness and hearing impairment/deafness are also examples of sensory disabilities.



## Living with IDD

Self-care	Community Use
Communication	Health
Mobility	Safety
Interpersonal Dynamics & Relationships	Leisure
Home Living	Education



### **Say**

- It is important to consider the adaptive functioning of a person living with IDD both from the person's and family's perspectives. Disabilities can impact functioning in many domains (as shown on the slide).



## Activity – Living with IDD



### **For Your Eyes Only**

*This is an Activity slide.*

*For Virtual Workshops:*

*Assign participants to breakout rooms. Ask them to take a few minutes on their own to fill out the form "Living with IDD" on their own and then have them discuss with their group what they came up with and add to their lists. Each group will be asked to report out to the larger group.*

### **For In-Person Workshops:**

*You will need ten large pieces of paper posted up around the room. You can use large sticky post-it pads or tape large pieces of paper on the walls. Each of the ten 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 standard-size post-it pads to the table. Each person will need several post-its and a pen. You will 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, read off the post-its, and ask if they would add anything.*

### **Say**

- *We are going to do an activity. As we are hanging these large pieces of paper on the wall, take a few of the post-its out on our tables. You will need a handful. Please think about how living with IDD affects the quality of life for the person and the family. Imagine people with various disabilities. What are some ways their daily functioning is impacted in these areas? Think about areas of challenge and think about how you, as a provider, can support people 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 area. 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 people 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 are 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.]*

## Activity – Living with IDD



### **Say**

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

*Summarize the activity with 3 points:*

1. Quality of life is vital to people with IDD and their families. As a provider, you always need to keep in mind how you can support and increase the quality of life for your clients.
2. Consider how each of these domains of functioning may be impacted by traumatic experiences.
3. As a provider, you will be/or are planning trauma-informed support, services, and treatment. Everything we have just read will need to be considered when you draw up service plans for your clients. We will be discussing Trauma-informed support, services, and treatment in Module 5.

# Living with IDD

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If you are participating in an in-person workshop, you may complete this activity as a group. You can use this page to write down any insights that you want to keep in mind in your own work.

If you are completing this course independently, think about how living with IDD effects the quality of life for the person and the family. Imagine people 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 people with IDD.

Self Care

Communication  
*- unable to ask for help*

Mobility

Social and Romantic Relationships

Home Living

Community Use

Health

Safety

Leisure

Education

## Living with IDD: A Family's Perspective

- Safety & health are ongoing concerns
- Adults with IDD may require extended parental and family involvement in care
- There may be increased stress in the home which leads to conflict between parents, siblings & other relationships
- Questions about the extent to engage in "disability culture"
- Concerns about how to help their person with IDD achieve a valued & happy life



- Caregivers of people with IDD are also “living with IDD.”
- What other challenges or concerns do they face? Take 2 minutes to discuss with the person next to you. *[Allow 2 minutes for discussion].*

Nora Baladerian’s book, *A Risk Reduction Workbook for Parents and Providers*, may be helpful to highlight as an example of a resource that parents may reference for guidance on developing a risk reduction plan for a person with IDD. Specifically, she outlines ideas for talking to children with IDD about before, during, and after a traumatic event.

- Development can still progress in adults with IDD; however, it may occur at a different pace.

- Traumatic experiences at any age and stage of development can interfere with a person's developmental accomplishments.

- When people endure multiple traumatic events over long periods of time they are especially likely to have difficulty meeting developmental tasks.



## Traumatic Experiences & IDD Can Disrupt Development



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### Facilitator Notes

#### Say

- Developmental levels often are not smooth across the domains of development.
- IDD may specifically alter the presentation of traumatic stress symptoms and vice versa.
- Both IDD and traumatic experiences can disrupt development by impacting the acquisition of developmental tasks.
- This is not to say that trauma stops development altogether, but it can act as a risk factor and slow down a developmental trajectory that the IDD has already slowed down.
- Traumatic stress reactions will vary depending on the developmental stage. For example, the reaction of a three-year-old child is different from that of a 35-year-old woman. The developmental stage is impacted because people exposed to trauma expend a significant amount of energy responding to, coping with, and coming to terms with the traumatic event. The energy spent doing so reduces a person's capacity to explore their environment and master age-appropriate developmental tasks. When a person experiences a traumatic event, the person must allocate resources to survival, typically dedicated to growth and development. The longer the traumatic stress goes untreated, the farther the people become from appropriate developmental pathways.
- Let us take a closer look at how IDD and traumatic experiences may impact responses at different developmental levels.

## Erikson's Theory of Development



Stage	Typical Age	Task	Existential Question
Infancy	0 – 18 m	Trust	Can I trust the world?
Early Childhood	2 – 4 yrs	Autonomy	Is it okay to be me?
Preschool Age	4 – 5 yrs	Initiative	Is it okay for me to do, move, and act?
School Age	5 – 12 yrs	Industry	Can I make it in the world?
Adolescence	13 – 19 yrs	Identity	Who am I? Who can I be?
Early Adulthood	20 – 39 yrs	Intimacy	Can I love?
Adulthood	40 – 64 yrs	Generativity	Can I make my life count?
Late adulthood	65 – death	Ego Integrity	Is it okay to have been me?



•Another framework we will 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 challenges for each age. He describes this in terms of key "conflicts" that a person experiences at a developmental stage. For this training, we have simplified Erikson's stages into the primary tasks for each developmental stage.

[READ A SUMMARY OF THE SLIDE]

•Note that this framework might not apply to families whose socio-cultural context differs. One could argue that Erikson's developmental challenges are based on a Eurocentric paradigm. Developmental abilities and expectations are shaped by cultural values and socio-political and economic contexts. It is important to explore the cultural values of a person and their family. •For example, traditionally collectivistic cultures may not value (individual) identity development and separation from family as much as more individualistic cultures.

•Given differences in developmental levels of adults with IDD, the trauma symptoms they experience may vary depending on the age and developmental level of the person during the trauma experience.

•There are specific periods during the brain's development that are most open to certain kinds of learning and development. When trauma occurs during one of these periods, it may show itself in specific ways. We will discuss the impact of trauma experienced across the lifespan to help us understand how an adult with IDD who experienced trauma early in life may be affected later in life.

## IDD & Trauma in Early Childhood



Developmental Tasks	Trauma's Impact
<ul style="list-style-type: none"> <li>Attachment to primary caregiver</li> <li>Development of visual &amp; auditory perception</li> <li>Recognition of &amp; response to emotional cues</li> <li>Develop greater independence &amp; capacity to assess danger</li> </ul>	<ul style="list-style-type: none"> <li>Changes in eating &amp; sleeping</li> <li>Become passive, quiet</li> <li>Heightened startle response</li> <li>Confusion about what's dangerous &amp; who to go to for protection</li> <li>Fear of being separated from familiar people/places</li> <li>Engage in regressive behaviors</li> </ul>

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Early childhood birth through the preschool years is crucial for the development of brain pathways that:

- Help children process what they see and hear/**visual & auditory perception**
- Enable children to recognize, analyze, and respond to emotional cues/**empathy**
- 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 develop a sense of self (e.g., their **self-concept & self-esteem**), which gains more significant momentum during middle childhood.
- Early childhood is also a time of great **motor** and **language** development.
- Some examples that may be present in young children are physiological solid and sensory reactions, becoming passive, quiet, or easily alarmed or startled, and 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 effect, most young children blame themselves for the traumatic event.
- One of the most significant developmental milestones of young children in developing secure attachments with caregivers and trauma symptoms often manifests insignificant attachment issues.
- Reject contact and avoid being touched
- Be confused about what is dangerous and whom to go to for protection, mainly 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 result from interactions with parents/caregivers, the impact on development can be particularly significant at this young age, especially on developmental tasks like attachment.

### For a person with IDD who experienced trauma as a young child:

- They may have more difficulty calming down after being scared; it may be harder to reassure them.
- Their 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 resulting in a lifetime of untreated trauma.
- The person may use withdrawal or become less responsive to fear, terror, and unsafe feelings.
- Developmental gains are at times more fragile for children with IDD. Following a traumatic experience, loss of recent gains like occupational skills) may be dramatic, and they may lose skill development gains.
- Additionally, the person may experience and express more negative affect, have trouble interacting with peers, become more aggressive, develop new fears, and display behavioral and/or emotional dysregulation.

*\*[Ask participants for additional ideas.]*

## IDD & Trauma in Middle Childhood



Developmental Tasks	Trauma's Impact
<ul style="list-style-type: none"> <li>Manage fears, anxieties, &amp; aggression</li> <li>Sustain attention for learning &amp; problem solving</li> <li>Control impulses &amp; manage physical responses to danger</li> </ul>	<ul style="list-style-type: none"> <li>Unwanted &amp; intrusive thoughts/images</li> <li>Preoccupation with moments from the traumatic experience</li> <li>Replay the traumatic event</li> <li>Develop intense, specific new fears linking to the original danger</li> <li>Oscillate between being avoidant &amp; reckless</li> <li>Sleep or concentration challenges</li> </ul>



### Say

- During the school years, the brain starts building the pathways that develop children's 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."
- 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 specific 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 input from parents, teachers, and other caregivers.
- During middle childhood, children reciprocate 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



## IDD & Trauma in Middle Childhood



Developmental Tasks	Trauma's Impact
<ul style="list-style-type: none"><li>▪ Manage fears, anxieties, &amp; aggression</li><li>▪ Sustain attention for learning &amp; problem solving</li><li>▪ Control impulses &amp; manage physical responses to danger</li></ul>	<ul style="list-style-type: none"><li>▪ Unwanted &amp; intrusive thoughts/images</li><li>▪ Preoccupation with moments from the traumatic experience</li><li>▪ Replay the traumatic event</li><li>▪ Develop intense, specific new fears linking to the original danger</li><li>▪ Oscillate between being avoidant &amp; reckless</li><li>▪ Sleep or concentration challenges</li></ul>



Cont.

**An adult with IDD** who has a traumatic experience in middle childhood:

- If the trauma was unrecognized or the effect under-appreciated, these “acting out” behaviors may have resulted in labels like ADHD, conduct disorder, or challenging behaviors.
- May have reduced receptive and expressive language skills, making 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 like math that requires focused attention
  - May have difficulty with peer relationships and vulnerability to persistent teasing, bullying/isolation from peers
  - *[Ask participants for additional ideas.]*

## IDD & Trauma in Adolescence and Young Adulthood



Developmental Tasks	Trauma's Impact
<ul style="list-style-type: none"><li>▪ Think abstractly</li><li>▪ Anticipate &amp; consider the consequences of behavior</li><li>▪ Accurately judge danger &amp; safety</li><li>▪ Increased impulse control &amp; ability to defer gratification by thinking through consequences</li></ul>	<ul style="list-style-type: none"><li>▪ May feel embarrassed or angry about bouts of fear &amp; exaggerated physical responses</li><li>▪ Difficulty imagining or planning for the future; decreased motivation for learning</li><li>▪ Low self-esteem &amp; helplessness</li><li>▪ Difficulties with trust</li><li>▪ Reckless &amp;/or self-destructive behaviors (e.g., drugs, cutting)</li></ul>

VCU WITH

### Say

- During adolescence, the brain continues to build connections and pathways that enable young people to think abstractly , including:
  - Imagine the future and anticipate and consider the consequences of their behaviors
  - Make realistic appraisals of what is dangerous and what is safe
  - Alter their current behaviors in order to meet their longer-term goals
- The primary task facing adolescents 13-18 and into young adulthood is to create a stable **identity** and to become a mature and productive adult. Adolescent development is based on learning acquired through relationships and past experiences. Youth use these experiences and their beliefs as a basis upon which to define themselves, make judgments about the world, and develop relationships with others.
- A child's identity is often an extension of their 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 significant to this process.
- At no time since birth does an individual undergo rapid and profound **physical changes** 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.

## IDD & Trauma in Adolescence and Young Adulthood



Developmental Tasks	Trauma's Impact
<ul style="list-style-type: none"> <li>Think abstractly</li> <li>Anticipate &amp; consider the consequences of behavior</li> <li>Accurately judge danger &amp; safety</li> <li>Increased impulse control &amp; ability to defer gratification by thinking through consequences</li> </ul>	<ul style="list-style-type: none"> <li>May feel embarrassed or angry about bouts of fear &amp; exaggerated physical responses</li> <li>Difficulty imagining or planning for the future; decreased motivation for learning</li> <li>Low self-esteem &amp; helplessness</li> <li>Difficulties with trust</li> <li>Reckless &amp;/or self-destructive behaviors (e.g., drugs, cutting)</li> </ul>

Cont.



- **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 shared values and beliefs. If an adolescent can make friends and belong to a mutually supportive peer group, he or she is likely to adjust in other areas of development successfully. Peers play the primary supportive role in emotional development. They help youth to begin to define who they are and how they fit into the broader community.
- And **romantic interest** become 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 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 future, instead "living in the moment" without regard to consequences

## IDD & Trauma in Adulthood



Developmental Tasks	Trauma's Impact
<ul style="list-style-type: none"><li>▪ Dialectical thought</li><li>▪ Intimate Relationships and parenting</li><li>▪ Social Inclusion</li><li>▪ Work and career</li><li>▪ Managing declining physical functioning/medical concerns</li></ul>	<ul style="list-style-type: none"><li>▪ Difficulty imagining or planning for the future;</li><li>▪ Decreased motivation for learning or working</li><li>▪ Difficulties with trust</li><li>▪ Isolation and social withdrawal</li></ul>

### Facilitator Notes

#### Say

In adulthood, the brain continues to develop and learn from experiences, particularly the ability to engage in Dialectical Thought. Dialectical thought assesses the complexity of situations and tries to resolve two opposing ideas: the desire to be independent and the desire to be taken care of. Adolescents may be quick to judge an idea as of right or wrong, good or bad. However, in adulthood, we become better able to weigh the pros and cons of ideas or situations with more flexibility.

During this time, adults with IDD may experience many transitions – transitions from school into work or other training programs, transitions from pediatric to adult healthcare systems, transitions to more independent living, and social interactions.

This is also a time when many adults experience the aging of their parents, resulting in additional transitions or loss of their parents, which can result in significant traumatic grief.

**CLICK OR PRESS SPACE BAR: Trauma's impact can include** Difficulty imagining or planning for the future; Decreased motivation for learning or working; Difficulties with trust; isolation, and social withdrawal

### Video Options

<https://www.youtube.com/watch?v=LCa02IgV0I0>

This video is a short documentary of people with developmental disabilities talking about what they like about working. This video is ~ 13 minutes. It can be used to start a discussion about adults with IDD and their need to work, be productive, be members of the community

<https://www.youtube.com/watch?v=-dDncNlVzwl>.

This video by RTC Media discusses the need for social inclusion, including rights to marry and work, for adults with ID. This brief video (~ 3 minutes) provides an example of healthy adult development and can be used as a back drop for how trauma might limit adult development by limiting opportunities for inclusion and healthy relationships.

## IDD & Trauma in Older Age



Developmental Tasks	Trauma's Impact
<ul style="list-style-type: none"><li>▪ Continue living independently as long as possible</li><li>▪ Managing energy and physical changes</li><li>▪ Changes in health, cognition, and memory</li><li>▪ Generativity</li><li>▪ Making sense of one's life</li></ul>	<ul style="list-style-type: none"><li>• Late-Onset Stress Symptomology (LOSS)</li><li>• Changes in cognition and memory</li><li>• Symptoms of trauma may be mistaken for delirium or dementia</li><li>• Decreased independence</li><li>• Difficulty making meaning of trauma in context of life</li></ul>

We now turn to a discussion of the developmental tasks of an aging person and the impact of trauma during this developmental window.

The good news is that the life expectancy of people with IDD has been increasing over the decades. Increased access to healthcare, enhanced community-based supports and services, and reductions in environmental and social barriers to participation in the community are just a few reasons that people with IDD are now living into their 60s and beyond.

Unfortunately, there is still work to be done as research has shown that life expectancy for adults with IDD is about 20 years less than the general population.

Older adults often strive to maintain as much independence as possible, and the ability to do so is associated with increased longevity. Older age comes with increased medical and physical challenges that require changes in routines and activity levels. Older adults may start to experience health, cognition, and memory changes, which may be distressing to some.

Critical psychosocial developmental tasks during this time include generativity and meaning-making.

Generativity is needed to be productive and give back to others, often to younger generations. It can include continuing to work, volunteer, care for others, and have meaningful social connections, parenting, and grand-parenting.

It is also a time when a person looks back over their life and tries to make sense of it or find meaning. Erikson called this “integrity versus despair.” To what extent can we look back over our lives and feel like it meant something.

## IDD & Trauma in Older Age



Developmental Tasks	Trauma's Impact
<ul style="list-style-type: none"> <li>Continue living independently as long as possible</li> <li>Managing energy and physical changes</li> <li>Changes in health, cognition, and memory</li> <li>Generativity</li> <li>Making sense of one's life</li> </ul>	<ul style="list-style-type: none"> <li>Late-Onset Stress Symptomology (LOSS)</li> <li>Changes in cognition and memory</li> <li>Symptoms of trauma may be mistaken for delirium or dementia</li> <li>Decreased independence</li> <li>Difficulty making meaning of trauma in context of life</li> </ul>

Cont.

### Older adults, with and without IDD, may be more prone to medical trauma, grief and loss related traumas, institutionalization, and/or elder abuse

We know the effects of trauma in older adults because of research with older Veterans.

Older adults who experienced trauma earlier in life may have Late-Onset Stress Symptomology (LOSS)—associated with increased thoughts and memories of early trauma. They may be more sensitive to new stressors such as retirement, loss of loved ones, or increased medical concerns.

There appears to be an association between traumatic stress and cognitive functioning in older adults, but the direction of that relationship is not well understood. Some studies have suggested that preexisting traumatic stress may increase the risk for dementia; others suggest that dementia may exacerbate PTSD symptoms.

It may be hard to identify trauma symptoms, like hypervigilance or flashbacks, because they may be mistaken for delirium or dementia.

Together, traumatic stress and the associated changes in mood, behavior, and cognition may lead to decreased independence and increased difficulty making meaning of their life. It is important to find ways to promote these healthy developmental tasks by increasing independence, connection with younger generations, and reflecting on and making sense of the person's life.

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## IDD & Trauma in Older Age



"Adults with Developmental Disabilities" <https://youtu.be/MGIEpswIE5w>

Recommended video:

<https://www.youtube.com/watch?v=MGIEpswIE5w>

This video shows the need for activities, relationships, and generativity for older adults with Developmental Disabilities.

**Activity –**  
*Putting It Into Practice—*  
*Case Vignettes: Trauma,*  
*IDD & Development.*




**For Your Eyes Only**

*This slide is an Activity. Assign each table a case. Participants will use a handout for this activity, **Putting It Into Practice—Case Vignettes: Trauma, IDD & Development.***

**Say**



I will introduce you to five different adult scenarios. We will refer back to these adults through the training.





**Introducing...**

- Jaqueline is a 34-year-old woman from El Paso, TX.
- Austin is a 22-year-old man from Cincinnati, OH .
- Joey is 30-year-old man from Wichita, KS
- Katie is a 35-year-old woman from Madison, WI
- Trevelyan is a 65-year-old man from Detroit, MI

### **Say**

- (Click the remote or press the space bar). Meet Jaqueline. She is a 34 year-old woman from El Paso, TX.
- (Click the remote or press the space bar). Austin is a 22 year-old man from Cincinnati, OH .
- (Click the remote or press the space bar). Joey is 30 year-old man from Wichita, KS
- (Click the remote or press the space bar). Katie is a 35 year-old woman from Madison, WI
- (Click the remote or press the space bar). Trevelyan is a 45 year-old man from Detroit, MI
- 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.]*

# CASE VIGNETTE

## JACQUELINE

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Jacqueline is a 34-year-old woman who grew up in the lower valley of El Paso, Texas. Jacqueline was diagnosed with Down's syndrome (trisomy 21) at birth and was identified with hearing impairment and a congenital heart defect early in her life. She was diagnosed with an intellectual disability in elementary school.



Jacqueline's parents divorced when she entered Kindergarten. She, her mother and two older sisters had no option but to move in and live with extended family members. They finally settled in and lived with Jacqueline's mother's sister. Jacqueline's mother was working two minimum wage jobs to save up for a place to live. She also contributed to her sister's household funds and her children's need. Jacqueline was often left in the care of her aunt, her older sister or an older cousin still living at home.

There were times during her childhood when occupational, speech therapy and doctor appointments were missed. Jacqueline's older cousin Robert, tended to play rough with her, sometimes leaving bruises and he frequently made fun of her speech. Jacqueline also cried a lot and had frequent tantrums at school and home. At those times, her aunt's boyfriend would send her to her room after yelling at her to stop crying and being such a bad girl.

Her mother eventually remarried and at the age of eighteen Jacqueline was placed in a group home.

In the group home where Jacqueline lives with 3 other women with disabilities, she began to experience waking in the middle of the night from nightmares. In response, sometimes evening staff would go into her room and just be with her until she was able to go back to sleep.

Jacqueline's sister visits every weekend and recently noticed that Jacqueline is very defensive to the touch and became physically aggressive when she tried to give her a hug. Jacqueline's sister also noticed that the sheets and bedding were soiled and had not been changed. Staff said that she has started wetting the bed again.

Jacqueline's sister is concerned with the aggressiveness and the care that Jacqueline may not be receiving by the staff in the group home.

# CASE VIGNETTE

## AUSTIN

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Austin is a 22-year-old male who was a healthy baby and developed normally for the first year of his life. At 18 months of age, his mother started to notice that Austin didn't seem interested in or to have curiosity about other children. He began playing with only a few select toys. Shortly before the birth of his younger brother, Austin stopped making eye contact and by the time he was 21 months old, he had ceased speaking altogether (or making any sounds except when he cried). He seemed to be withdrawing more and more into his own world. Progressively, loud sounds were distressing and he began plugging his ears, eventually loud noises that never used to bother him—became unbearable. Along with his auditory hyper-sensitivity came sensory issues in all areas. When he was 2 1/2, he began showing signs of “visual stimming” (repetitive visual stimulation) and very pronounced obsessive compulsive behaviors. Austin was formally diagnosed with autism spectrum disorder by a pediatric neurologist.



Austin grew up in a bilingual household. His mother speaks English to him and his father speaks Hungarian. At the age of three, he was found to be farsighted and given glasses. At 3 1/2 years he was placed in a special education preschool. He was entirely nonverbal by that time. Over the summer he attended an Early Education Center. Austin received private speech therapy through Easter Seals in addition to public school and began speaking after the weekly speech therapy visits. His speech was limited to “no,” “bye,” and “hi.” He would repeat words if asked and also use single words to request familiar things. Occupational therapy was provided intermittently throughout this time. These interventions became a regular part of his life throughout his early childhood and elementary years.

At the age of 12-years-old, Austin's parents stopped his therapies and interventions. They decided he needed a break and felt he had made great progress and was functioning well at school and home. His parents wanted Austin to be in general education for at least some of his classes. In middle school he began to run away from the school and school security would call his parents to come and pick him up once they had restrained and isolated him. Austin began to show more aggression as he entered high school at home and school.

In high school and through his transition age school years Austin began to see a psychotherapist on a weekly basis to help him with managing his emotions and interactions with peers. Austin was diagnosed with Bi-Polar disorder when he was evaluated by a psychiatrist his senior year of school. As Austin transitions out of high school at 22-years-old, his parents would like him to live on his own and are working towards a plan for him to live close to them in his own apartment. Austin has had difficulty making and keeping friends and his parents hope by living on his own it will help him achieve some social connections.

# CASE VIGNETTE

## JOEY

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Joey, a 30-year-old with an intellectual disability from Wichita, KS was taken to have his blood drawn by his mother who typically accompanies him to medical visits a few years ago. The phlebotomist greeted Joey and his mother and escorted Joey to the chair for the blood draw. He then informed Joey's mother that she needed to wait in the waiting room. Joey's mother began to explain that she always accompanied Joey during his medical procedures, but the phlebotomist did not let her finish her explanation.

He stated that all parents are required to wait in the waiting room and he shut the door as she stepped out.



Joey then got out of the chair and began to pace around the room. The phlebotomist asked him to sit down, but Joey said he wanted to leave. The phlebotomist said that they would leave as soon as he sat down and completed the procedure. Joey hesitantly sat down, but was squirming in his seat and fidgety with his hands. The phlebotomist insisted with an angry tone that he hold still. Frightened, Joey began to leave his seat. The phlebotomist blocked him and grabbed his arm and held it down. He said to Joey "if you don't hold still, you're not going to be able to leave." Joey became increasingly fearful and began to yell and cry for his mother. The phlebotomist proceeded to continue the blood draw restraining his arm and body.

Now, Joey becomes upset whenever he has to go to a doctor's appointment. He cries and tries to hide and sometimes becomes aggressive. As a result, he has been missing regular medical appointments and his mother is worried that his health is declining.

# CASE VIGNETTE

## KATIE

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Katie is 35-year-old and has been working at her job in an office for almost a year. She has done well organizing supplies and keeping the conference rooms prepared for meetings. She gets along well with other employees and typically likes going to work each day. She is assisted by a job coach that supports her to stay focused on her tasks. While she sometimes gets distracted, she is congenial with all those supporting her.



Katie's job coach recently went on maternity leave for several months. The new job coach was a kind young man who was committed to helping Katie. Soon after he started the job, Katie became agitated on the job, wasn't relating well to other employees, and wasn't performing her tasks as was expected of her. Anytime the new job coach approached her to assist, Katie got angry and told him to go away.

Katie's employer noticed the changes and suggested that they consult with Katie's case manager to gain insight into what may have generated the change in Katie's work experience. It was discovered that in high school Katie had been sexually assaulted by a young man of similar size and build as the new job coach. Recognizing that Katie didn't feel safe (even though she was safe), enabled those supporting her to get her the support she needed to work through her fears.

# CASE VIGNETTE

## TREVELYAN

---

Trevelyan is a 65-year-old man from Detroit, MI. He has a bright smile and loves physical activity. Trevelyan has autism and lives in a residential center for people with developmental disabilities and has since he was 13 years old when his mother felt that she could no longer care for him at home due to his size and aggressive behaviors. Trevelyan does not use verbal communication. He knows a few words in sign language (“please,” “thank you,” and “sorry”). After bringing him to the residential center as a child, his mother and other family members have rarely visited him, stating that they couldn’t afford to take time off work or travel the 1.5 hours to the center to visit him.



His case file indicates that he grew up in an impoverished area and that he likely had limited access to appropriate interventions, such as applied behavior analysis, speech and language therapy, or occupational therapy. Not much is known about his home life prior to coming to the center. Because he frequently exhibits aggressive behaviors towards staff and peers, he is often on one-to-one supervision. When he was younger, restraints and basket holds were frequently used in response to his aggressive behaviors.

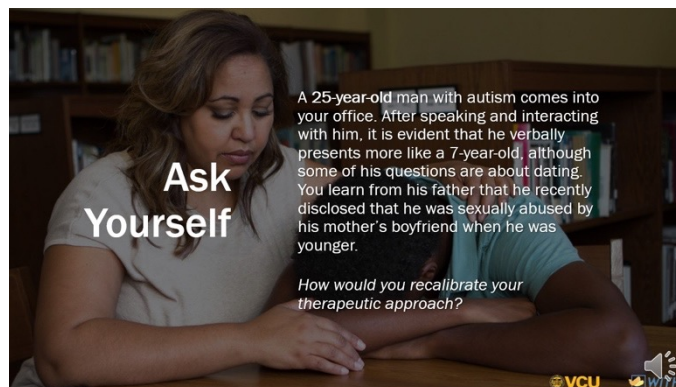
A behavioral analysis indicated that Trevelyan is more likely to act aggressively when he isn’t allowed to have a preferred snack (either it is unavailable or belongs to another resident), when another resident is doing something that he wants to do, or to escape demanding tasks at his day program. His behavior plan has focused on redirecting him to other tasks and minimizing task demands with limited success. However, there are other times when he will push staff, run out of the building, or start slamming into doors and walls with no apparent antecedent. It is assumed that he becomes “overstimulated” because of his autism. Staff are frequently injured and turnover has been high, and many staff report that the stress and injuries from working with Trevelyan is a major reason they quit.

# PUTTING IT INTO PRACTICE

## CASE VIGNETTES: TRAUMA, IDD & DEVELOPMENT

Read the case vignette your group has been assigned and identify the ways in which trauma and intellectual and developmental disability are/may disrupt development.

- Identify any behaviors and responses related to intellectual and developmental disability.
- Identify any behaviors and responses related to traumatic experiences.
- What are other ways that intellectual and developmental disability and traumatic experiences may disrupt typical development for the age range (e.g., emerging adult, adult, older adult) of the case you've been assigned?



### **Facilitator Notes Say**

•Throughout this module, we have discussed the complexity of development, the types of development, the typical developmental stages, and how trauma during these developmental stages may have impacted adults with intellectual and developmental disabilities. We will consider another example here.

Read the slide.

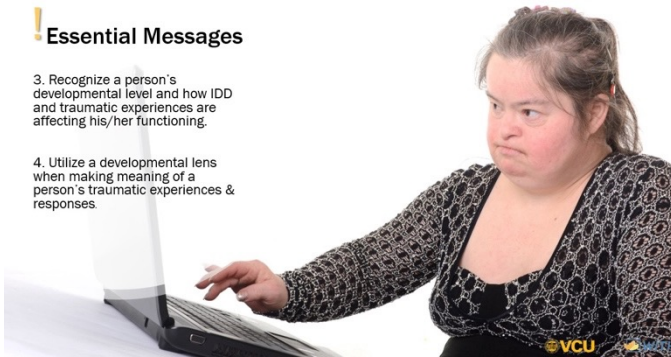
- Quickly, just off the top of your heads, what are you thinking?
- The adult may act like a 7-year-old in some respects but a 25-year-old in others. He has developmental delays and disabilities that will need to be accommodated.
  - You will have to recalibrate your therapeutic approach by considering developmental tasks for both 7- and 25- year old. Please discuss with your group how you would go about adjusting your approach for this client? Is there information you want or need? Who else do you would like 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 would like to learn.]*



## ! Essential Messages

3. Recognize a person's developmental level and how IDD and traumatic experiences are affecting his/her functioning.

4. Utilize a developmental lens when making meaning of a person's traumatic experiences & responses.



### Say

To recap, the Essential Messages discussed in Module Two include:

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

## What Can a Provider Do?

- Ask questions and gather information (formally or informally) to understand the person's developmental age & how IDD is affecting his/her functioning.
- Identify IDD-related support needs of the person & family.
- Identify how living with IDD is affecting the quality of the person's life.



### **Say**

(Click the remote or press the space bar)

Here are some things that you as a provider can do to address the concepts that we just discussed in Module 2. Let us take a few minutes to think about what you can do specifically in your role and your organization to address any one of these points.

## Activity – Action Planning

Essential Messages 3 & 4



### **For Your Eyes Only**

*This is an Activity slide, which will recur at the end of each Module. This is the opportunity for participants to reflect on their practice and think concretely about what they can enhance or do differently, based on the information 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 relevant strategies to their role.*

**Say** Pull out your handout titled **Action Planning: Essential Messages 3 & 4**. This is your opportunity to think about how you will 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). 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 strategy using the SMART objective format, you are welcome to do that. *[Allow 7 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.]*

# ACTION PLANNING

## ESSENTIAL MESSAGES 3 & 4

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Think about the person you identified at the end of Module 1 that connects you to this work. What can help that person and other adults with IDD who have experienced trauma? (Put an “X” in up to 3 boxes next to the ideas you think you would MOST like to emphasize in your daily practice.)

### 3

#### ESSENTIAL MESSAGE 3

Recognize a person’s developmental level and how IDD and traumatic experiences are affecting his/her functioning.

- ☐ Over the next 3 months, I will identify ways in which **trauma and IDD have disrupted development** for at least 3 adults with IDD. I will review these areas each time I meet with these them.
- ☐ Over the next 3 months, I will identify at least one **alternative way of communicating/teaching a therapeutic skill** (e.g. deep breathing, muscle relaxation) to use in place of, or in addition to, verbal communication for at least 3 adults with IDD. I will practice the chosen skill with them each time we meet.
- ☐ Over the next 3 months, I will review my **bibliotherapy resources** to determine if I have enough books to share with adults at different developmental levels about at least 3 different types of trauma.

### 4

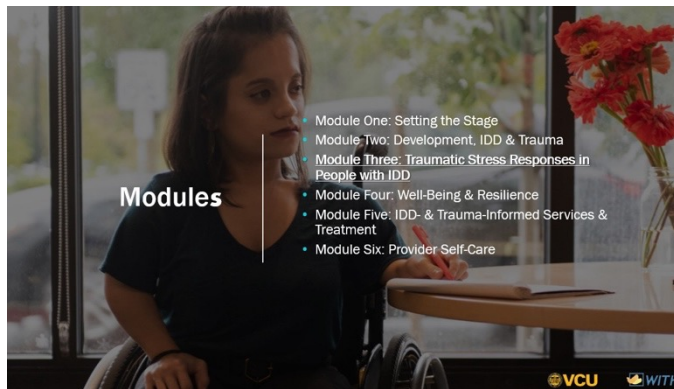
#### ESSENTIAL MESSAGE 4

Utilize a developmental lens when making meaning of a person’s traumatic experiences and responses.

- ☐ Over the next 3 months, I will identify how **living with IDD** is affecting the quality of life in specific areas (e.g., self-care, communication, etc.) for at least 3 adults with IDD who have had traumatic experiences. For each of these people, I will develop a plan, with the person and caregivers that addresses these specific areas. I will review this plan each time I meet with them during this 3-month period.
- ☐ Over the next 3 months, I will learn a new method of assessing the person’s **intellectual abilities** that may be better-suited to working with an adult with IDD who has had a traumatic experience (e.g., learn an IQ test that is normed on a more diverse population, non-verbal methods, etc..).
- ☐ (Write my own.) Over the next 3 months, I will...

# Module Three

Traumatic Stress Responses in People with IDD



## Facilitator Notes

### Say

- We will now go into more detail on the traumatic stress response and how it may impact people with IDD specifically.

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Module Three: Learning  
Objectives

**What Will I Learn  
Today?**

---

1. Identify the types of events that can cause traumatic stress.
2. Define traumatic stress and trauma-related disorders.
3. Identify how traumatic experiences and their responses affect people with IDD.



**Say**

- After completing this module, you should be able to do the following:
  - 1) Identify the types of events that can cause traumatic stress
  - 2) Define several types of trauma-related disorders
  - 3) Identify the ways in which trauma affects people with IDD.

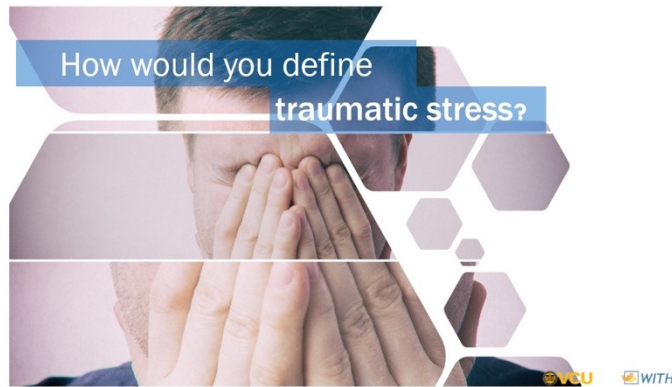
## Recognize

the signs and symptoms of trauma



The second R of trauma is to Recognize the signs and symptoms of trauma. It is necessary to broaden our understanding of behavior from observable proximal factors, such as those we can see in the person's immediate environment, to consider the distal influence of trauma and the potential for subtle trauma cues and reminders that might not be readily observed..





### **For Your Eyes Only**

- *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.*

### **Say**

- *How would you define traumatic stress? Just shout out whatever comes to your mind. [Allow participants to shout out responses.]*

## Types of Traumatic Experiences

- Single traumatic experience (e.g., serious car accident, disasters)
- Experiences that occur together (e.g., domestic violence & physical abuse)
- Experiences that can extend over time (e.g., sexual abuse)
- Mass trauma (e.g., natural disaster, civil unrest, pandemic)
- Experiences that are a mixture of the above



### For Your Eyes Only

- *There are several animations on this slide. You will have to initiate the animations for the slide content. Please be aware of when you will need to click the remote or press the space bar.*

### Say

- *(Click the remote or press the space bar).* Remember back in Module 2 when we discussed how the type of traumatic event and age at which it occurred is important to understand its effect? When we think about the types of traumatic experience, it can matter whether it was...
- *(Click the remote or press the space bar).* **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 people with IDD may be particularly impacted by the physical nature of their disability. For example, if a person 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.
- *(Click the remote or press the space bar).* **Experiences that occur together.** For example, a person might be in a home where he/she is a witness or is a victim of both physical and emotional abuse.
- *(Click the remote or press the space bar).* **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.

## Types of Traumatic Experiences

- Single traumatic experience (e.g., serious car accident, disasters)
- Experiences that occur together (e.g., domestic violence & physical abuse)
- Experiences that can extend over time (e.g., sexual abuse)
- Mass trauma (e.g., natural disaster, civil unrest, pandemic)
- Experiences that are a mixture of the above

Cont.



•(Click the remote or press the space bar). **Mass Traumas** are those that affect entire communities – these may include natural disasters, civil unrest, and pandemics. This recording is being made during the global COVID-19 pandemic, while many parts of the country are also experiencing uncontrolled wild fires and civil unrest due racial injustice. These types of traumas bring complex challenges, not only because they extend over time and include multiple types of traumas (such as isolation, deprivation, actual or feared infection, loss of home, sheltering in place with an abuser) but they affect the entire ecological system. We are only beginning to understand the impact of these events on people with ID and their families, but the effects are expected to be profound and long-lasting.

•(Click the remote or press the space bar). **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 person depends on for caregiving assistance and safety, it creates additional challenges.

•Additional examples of traumatic experiences that people with IDD may face:

•**Medical Trauma.** It's important to note that interactions with primary medical practitioners may in and of themselves be traumatic for people with intellectual disabilities. Medical-related trauma constitutes another important consideration for this population. Given frequent physical co-morbidities that may require procedures and invasive physical examinations that the person may have difficulty understanding and communicating his/her feelings about, medical trauma may be an important factor to consider when working with people with IDD.

•**Systems Trauma.** People with IDD and their families may experience repeated discrimination and alienation by the systems that are supposed to be providing them with services.

## Type & Timing Matters



- It is important to recognize that traumatic experiences may occur at different time points. For some people, the traumatic experience may occur after the IDD has been diagnosed, at some later point in the person'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. In this training, we will discuss how these, and other factors, play a role in the process of recovery.
  - Life experiences prior to trauma also affects how the trauma is experienced, as well as post-trauma recovery.
- For example, an adult experiencing a car crash who has lived with a nurturing family is going to respond differently from someone who has experienced neglect by the caregiving system early in life. The reactions of others to the trauma can have profound impacts as well. For example, an adult who discloses sexual abuse and is believed and supported will have different outcomes compared to someone who discloses abuse and is met with disbelief, blame, or shame.

## What is Traumatic Stress?



VCU WITH

### Facilitator Notes

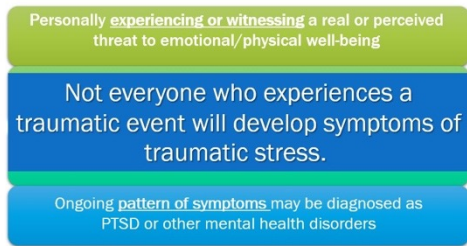
#### For Your Eyes Only

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#### Say

- Traumatic stress occurs when people personally **experience or witness** a real or perceived threat to his/her emotional/physical well-being. It is important to distinguish 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, 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 people with more severe disability as their sense of safety depends on their perceived safety of their attachment figures or caregivers. A person'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.
- (Click the remote or press the space bar). People 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 person, and this intensity registers in the person's body and mind.
- A person's response to an event is based, in part, on the person's perception of the danger and lack of protective action. As a result people with IDD may have a lower threshold for what is considered traumatic because they may have diminished capacity to understand what has happened or to protect themselves.
- When people have a traumatic experience, they react in both physiological (heart rate may increase, sweat, feel agitated, hyperalert, become emotionally upset) and psychological ways.

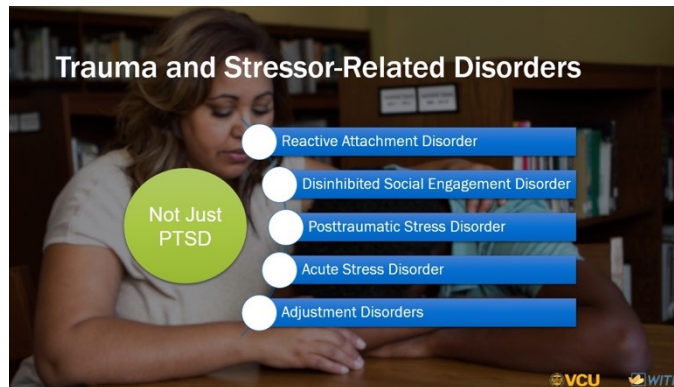
## What is Traumatic Stress?



Cont.



- (Click the remote or press the space bar). •**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.
- People who suffer from traumatic stress often have these types of symptoms when reminded in some way of the traumatic event.
- At no age are people immune to the effects of traumatic experiences; even infants and toddlers can experience traumatic stress and can affect them into adulthood.
- Although many of us may experience reactions to stress from time to time, when a person is experiencing traumatic stress, these reactions interfere with his/her daily life and ability to function and interact with others.
- For people who do experience traumatic stress, there are a wide variety of potential consequences.
- The way that traumatic stress manifests will vary from person to person and will depend on the person's age and developmental level.
- (Click the remote or press the space bar). Some of these people may develop **ongoing symptoms** that are diagnosed as post-traumatic stress disorder (PTSD), which we will discuss in further detail later in this Module.
- (Click the remote or press the space bar). Not everyone who experiences a traumatic event will develop symptoms of traumatic stress. Whether or not a person does, depends on a range of factors (e.g., availability of supportive attachment figures, history of previous trauma exposure).
- Now that you've seen the definition is there anything you'd like to add to our list before we move forward? *[Allow participants to shout out any remaining answers they'd like to add].*



Many people think of Posttraumatic Stress Disorder (PTSD) when they think of trauma. And while PTSD is a common reaction to traumatic stress, there are several others types of reactions that should be considered too.

These include:

Reactive Attachment Disorder

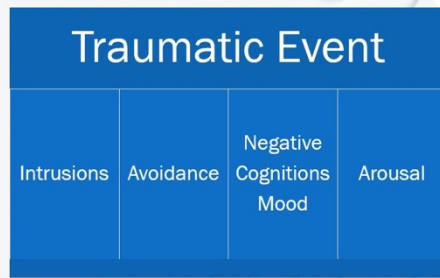
Disinhibited Social Engagement Disorder

Posttraumatic Stress Disorder

Acute Stress Disorder

Adjustment Disorder

## Criteria for PTSD



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### Facilitator Notes :

#### For Your Eyes Only

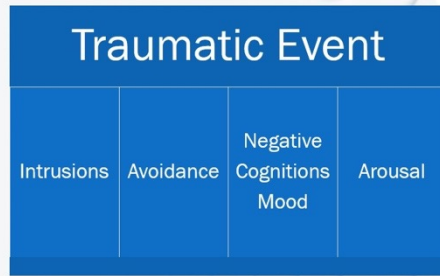
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#### Say

- (Click the remote or press the space bar) 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.
- (Click the remote or press the space bar) 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.
  - people may experience intense emotional distress in response to reminders or may experience renewed physical reactions.
  - In both cases, it may be hard for the person to calm down afterwards.
- (Click the remote or press the space bar) Third, the person 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.
  - people do not always have a choice about where to go, who to be with or hearing what others are talking about, especially people with IDD. They may be frustrated in their efforts to avoid painful experiences that can then show up as aggression, withdrawal, constriction of activity and affect, or what seems like oppositional or other challenging behavior.



## Criteria for PTSD



Cont.

- (Click the remote or press the space bar) Fourth, the danger, violence and seeming lack of protection can cause people to **expect** other bad things to happen, to judge something to be wrong with themselves or to expect that caregivers will not be able to protect them in ways they know they need.
  - People 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 people who have experienced trauma 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.
- (Click the remote or press the space bar) 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 people to have irritable behavior and angry outbursts, including verbal and physical aggression toward people or objects.
  - Rather than avoid situations, people 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, working or other focused activities difficult.
  - People who have experience trauma 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.
    - People who are not getting restful sleep are often irritable and have trouble learning.
- (Click the remote or press the space bar) Traumatic experiences lead to **impairments** in functioning. For example, important relationships with caregivers, siblings and friends may be affected, or they may experience difficulties in occupational performance, behavior and other developmental goals.
  - These may include loss of prior developmental gains (talking, bowel training etc..), derailments in development that can lead to changes in motivation and ambitions.
- Accurate diagnosis is essential to identifying appropriate treatment.

## PTSD with Dissociative Symptoms



### Depersonalization

- Feeling detached or outside of body
- Feeling of time moving slowly



### Derealization

- Unreality of surroundings  
World around individual is unreal, distorted, dreamlike

May manifest as acting-out of the trauma, self injury, agitation, aggression, or disorganized behavior in people unable to verbalize these unusual experiences



PTSD can also be associated with dissociative symptoms. These can include depersonalization and derealization.

Depersonalization is the feeling of being detached or outside of part or all of one's body or the feeling of a sense of feeling time moving more slowly. Derealization is a sense of unreality, like the world around oneself is unreal, distorted or dreamlike.

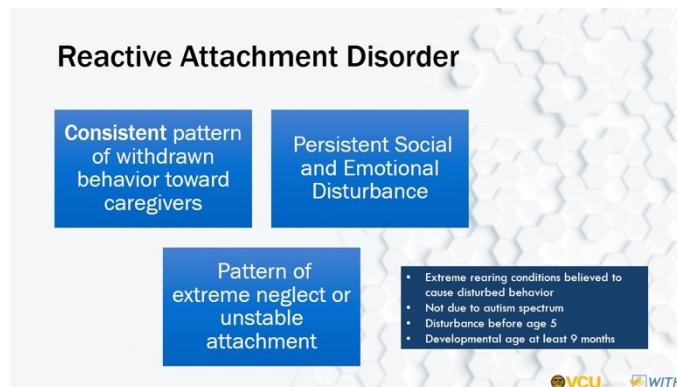
For people with IDD, it may manifest as acting out, aggression, agitation, self-injury or other disorganized behavior. Depersonalization and derealization may also be a symptom of seizure disorders, so an appropriate diagnosis is important.



Acute Stress disorder is very similar to PTSD. ASD symptoms include

- Intrusion
  - Distressing Memories
  - Distressing Dreams
  - Dissociative Reactions/Flashbacks
  - Distress to Cues
- Negative Mood
  - Inability to Experience Positive Emotions
- Dissociative Symptoms
  - Depersonalization/Derealization
  - Inability to Recall
- Avoidance
  - Avoidance of Memories, Thoughts, or Feelings
  - Avoidance of External Reminders
- Arousal
  - Irritable Behavior
  - Hypervigilance
  - Problems Concentrating
  - Sleep Disturbance
  - Exaggerated Startle Response

The biggest difference is the timing and duration. Acute Stress Disorder symptoms last for less than 1 month. Once the symptoms continue beyond 1 month, a diagnosis of PTSD is considered.



Reactive Attachment Disorder, sometimes called “RAD” is caused by significant disturbance in one’s ability to form health attachments to others. It is caused by extreme rearing conditions, such as ongoing abuse, neglect, or institutionalization occurring in infancy and early childhood (before age 5). Symptoms of RAD include:

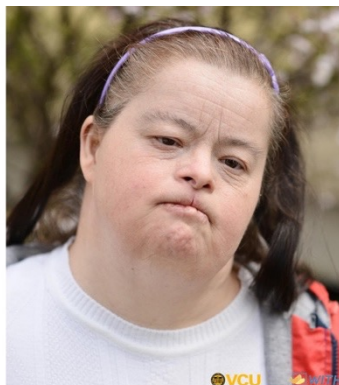
- A. Consistent pattern of withdrawn behavior toward caregivers
  - 1. Lack of developmentally appropriate seeking of comfort when distressed
  - 2. Lack of response to comfort when distressed
- B. Persistent Social and Emotional Disturbance
  - 1. Minimal social and emotional responsiveness to others
  - 2. Limited positive affect
  - 3. Episodes of unexplained irritability, sadness, or fearfulness during nonthreatening interactions (not during transitions or trauma reminders)
- C. Pattern of extreme neglect or unstable attachment
  - 1. Social neglect or deprivation
  - 2. Repeated changes in primary caregivers
  - 3. Rearing in unusual settings that limit attachment

Because diagnosis of RAD involves patterns of disrupted attachment behavior, it also requires that a person have a developmental level of approximately 9 months, when one would be expected to have the capacity to develop attachments.

RAD and ASD are both associated with social and emotional disturbance, and may "look" very similar in many ways. The history of extreme child rearing environment, such as neglect, institutionalization, or frequent changes in foster care, is the primary distinction. They are distinguished in part by the presence of restricted interests or ritualized behaviors, and social communication. For example, people with ASD have difficulty with goal-directed social communication, whereas people with RAD are not. People with ASD are also able to exhibit attachments to caregivers. People with ASD may also be diagnosed with RAD if they have experienced the pattern of unstable attachments in early childhood and lack attachment behaviors as well.

## Traumatic Stress and Other Diagnoses

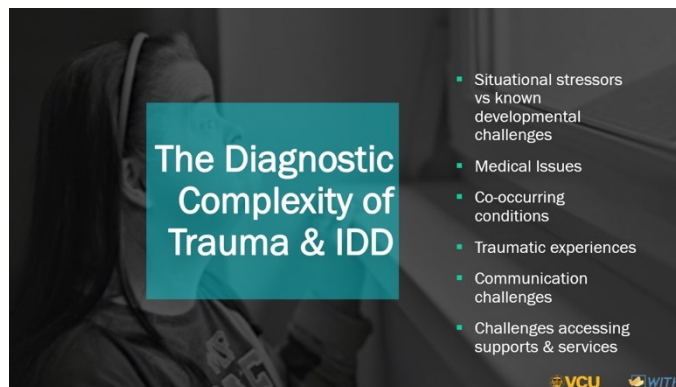
- Posttraumatic stress & grief reactions can develop into other mental health conditions & diagnoses over time (e.g., separation anxiety & depression)
- Exacerbate preexisting mental health problems
- Reactions to trauma reminders may sometimes result in misdiagnoses
- Competent assessment is critical for accurate diagnosis, and effective intervention



## Facilitator Notes

### Say

- Posttraumatic stress and grief reactions can develop into other psychiatric disorders over time, separation anxiety, and depression.
- Posttraumatic distress can also exacerbate preexisting mental health problems including depression and anxiety. Awareness of the broad range of a person's potential reactions to trauma and loss is essential to competent assessment, accurate diagnosis, and effective intervention.
- However, sometimes people with IDD 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 people 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 person's reaction to a trauma reminder, which can result in withdrawn, aggressive, reckless or self-injurious behaviors.
- For people with developmental disabilities who have experienced trauma there are additional challenges in assessing their symptomatology:
  - Symptoms may change as developmental functions emerge and so we need to use different measures at different developmental stages depending on their functional level
  - Caregiver reports are often relied upon during diagnosis, but different caregivers may not agree, caregivers may not be forthcoming, or they may themselves have misperceptions of the causes of symptoms.
  - Current diagnostic criteria may not be appropriate for people.
- It is vital that assessments be developmentally-guided, grounded on an ecological approach (assessing the functioning of each level of the ecological system) and include a thorough psychosocial history.



### Say

- When working with a person with IDD who has experienced trauma, 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. People 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 person with communication deficits.
- People 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.
  - How do agencies and avenues of care adjust to additional requirements of a person with IDD? Now add on top of that one who has also been traumatized?
  - Caregivers of people with IDD often report unrelenting stress when they cannot obtain the help their loved one needs.

## 12 Core Concepts



### Facilitator Notes

#### Say

The National Child Traumatic Stress Network, which was established by Congress in 2000, developed the 12 Core Concepts for Understanding Traumatic Stress Responses in Children and Families. These concepts guided the Road to Recovery toolkit for children with IDD, and we believe these core concepts apply to adults with disabilities, with some modification, as well.

We'll review each of these concepts in the next slides



## Core Concept 1: Complexity

"There's a lot going on in the person's mind and body."

### For a person with IDD

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.



## For Your Eyes Only

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

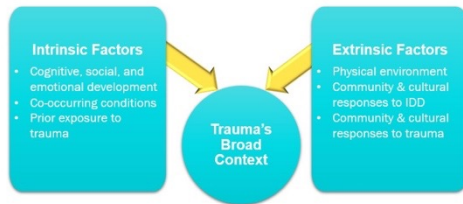
**Say** • The 1st Core Concept for understanding traumatic stress responses in adults with IDD is: **Traumatic experiences are inherently complex.**

- In general, there are **different moments** within a single traumatic experience.
- A person **appraises** the danger, emotionally responds, physically reacts, and considers what is needed to gain protection or end the threat.
- A person's **reactions are active and dynamic** in response to changes as an event unfolds.
- A person's reactions are influenced by their developmental level, prior trauma and loss experiences, culture, and personal strengths and vulnerabilities.
- The way the person views and responds to the world reflect expectations about danger, safety, and protection from a history of multiple trauma and loss experiences.
- Appreciating the complexity of a person's experience enhances a fuller understanding of the person
- (Click the remote or press the space bar). **For a person with IDD:**
- These moment-to-moment reactions can be even more complex due to physical or communicative limitations that affect the range of possible protective actions **during the traumatic experience.**
- Cognitive limitations can alter the understanding and meaning of what is happening. Understanding the functional limitations of the person helps to determine the potential impacts.
- People with IDD are vulnerable because they may not appraise danger in the same way that a person without IDD may appraise threat.
- They may require more supervision or need 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.
- A question for providers is how does someone with this set of disabilities understand what happened to them?
- A question for parents/caregivers is how much to explain to the person about what happened to them & protect them from future danger?



## Core Concept 2: Life Experience

*"What the person brings to the experience from within and from the outside world effects the person's response."*



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### Say

- The 2nd Core Concept for understanding traumatic stress responses in a person is: **Trauma occurs within a broad context that includes a person's characteristics, life experiences, and current circumstances.**
- Trauma occurs within the general ecology of a person's life composed of both intrinsic (or internal) and extrinsic (or external) factors.
- (Click the remote or press the space bar) **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 illness.
- (Click the remote or press the space bar) **Extrinsic factors** include the surrounding ecology of family, community, including their current functioning, available resources, and level of threat.
- These factors help shape a person's expectations regarding danger, protection, and safety.
- It is vital to identify and address these internal and external factors to understand a person's traumatic experiences and facilitate their recovery.

## Core Concept 2: Life Experience

*"What the person brings to the experience from within and from the outside world effects the person's response."*

For a person with IDD  
It is important to understand the traumatic experience within the context of how IDD affects the person's everyday life.



VCU WITH

### For an adult with IDD:

- A provider needs to understand the surrounding circumstances of the person with IDD (the ecology of the individual), as opposed to only knowing what happened (i.e., what the traumatic experience was). For the person with IDD, life experience may refer 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 person's care, related to his/her IDD?
- What was the context prior to the trauma?
- 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 person, family, provider and community context.
- What is the current context? Examples:
  - For a person who is in a wheelchair and lives in a violent neighborhood, the context of an assault is different than if the person lived in a safe neighborhood.
  - A person with autism may not read social cues correctly and misinterpret a benign event or miss one that was damaging.
  - Some adults 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 adults also experience the world through their caregiving relationships, and are profoundly affected and threatened by witnessing trauma experienced by a parent/caregiver.
  - For people 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 caregivers' protective, comforting, or regulating capacities are impaired (whether due to the caregiver's own trauma, mental health, staff turnover, organizational policies, etc.). Alternatively, when parents/caregivers are sensitive, attuned, and responsive, they can help buffer the effects of trauma on the person.
- 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?

## Core Concept 3: Reminders & Adversities

*"What's the world like that the person is living in afterwards?"*



For a person with IDD

Trauma may add to significant secondary adversities related to IDD experienced by the person and family that existed prior to the traumatic experience.

VCU WITH

### Facilitator Notes :

#### For Your Eyes Only

•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.

#### Say

•The 3rd Core Concept for understanding traumatic stress responses in adults and families is: **Traumatic events often generate secondary adversities, life changes, and distressing reminders in a person’s daily life.**

•Traumatic experiences can set in motion a cascade of changes in a person’s that can be challenging. These can include changes in where they live, where they work and socialize, live with, and their daily routines. They may now be living with injury or additional 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, its circumstances, and its aftermath.

•They may be reminded by persons, places, things, situations, anniversaries, or feelings such as renewed fear or sadness. Physical reactions can also serve as reminders; for example, increased heart rate, bodily sensations, or feelings of pain may bring back a flood of memories of the traumatic experience. This is particularly important because these internal cues may not be readily apparent to caregivers and may be missed in behavioral analysis. They may appear to come “out of the blue” when in reality, something is triggering a traumatic memory.

•Identifying the person’s responses to trauma and loss reminders is an essential tool for understanding how and why their distress, behavior, and functioning often fluctuate over time.

•Trauma and loss reminders can reverberate within families, among friends, in the workplace, and across communities in ways that can powerfully influence the ability of adults, families, and communities to recover. Addressing trauma and loss reminders is critical to enhancing ongoing adjustment.

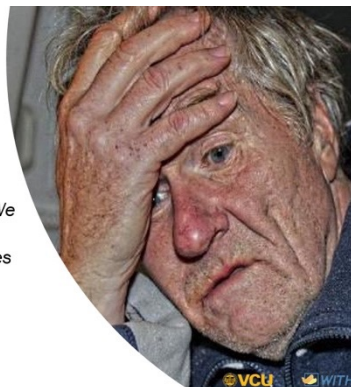
•(Click the remote or press the space bar). **For a person with IDD:**

•Adults with IDD and their 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, adult protective services involvement/investigations). The combination can further tax already stressed coping resources of the person and their caregivers.

## Trauma Reminders

*"For the longest time we couldn't understand why Billy would get so agitated for no apparent reason. We had no idea that the perfume his personal care attendant sometimes wore reminded him of his assault years ago."*



## For Your Eyes Only

- Have a participant read the quote.

### Say

- 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. People can have the same responses/reactions to a reminder as to the actual traumatic event itself.
- It is not uncommon for typically developing adults or adults 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. An important maxim is, **"all behavior is communication."**

#### Core Concept 4: Wide-Ranging Reactions

*"A person's reaction to a traumatic event varies greatly."*

##### For a person with IDD

Recognizing reactions to trauma in adults with IDD can be complicated by the wide-ranging expressions of their disabilities.



#### Say

- The 4th Core Concept for understanding traumatic stress responses in adults and families is: **People can exhibit a wide range of reactions to trauma and loss.** Given the complexity of trauma and loss experiences, adults may manifest their distress through a range of reactions, including post-traumatic stress, dissociation, grief, depression, separation anxiety symptoms, among others. These reactions may include bodily sensations and physical symptoms like nausea, stomachaches, headaches, muscle tension, and fatigue.
- Over time, a person's distress reactions may decrease or consolidate into a formal mental health disorder.
- The challenges of secondary adversities and life changes may intensify the person's reactions to traumatic experiences contributing to secondary sources of distress for adults, leading to additional worries, demoralization, depression, behavioral problems, and substance abuse. Also, adults with pre-existing mental health conditions may be especially vulnerable to experiencing an exacerbation or renewal of symptoms.
- It is essential to understand how these reactions and symptoms may take a toll on a person's daily functioning and developmental progression. It is also important to consider how a person's developmental level may influence their expression of distress. The disturbances in development can include loss of developmental achievements and ability to establish relationships, developing a sense of self, physiological stress-response system, affect expression and regulation, interference with readiness to take on new developmental tasks, or inappropriate behavior that introduces significant risk.
- (Click the remote or press the space bar). **For a person with IDD:**
- Traumatic experiences need to be understood in light of IDD.
- An adult 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 does not address the underlying traumatic experience, it could exacerbate the person's trauma response.
- In adults with minimal communication, distress may be signaled by exacerbating an old behavior (like screaming or head banging) or increasing non-specific behavior (like pacing).
- Trauma & loss experiences can interact with other behaviors (e.g., aggression) that disrupt fragile gains in impulse control that have been made. For example, aggressive behavior was successfully addressed, and then the traumatic experience occurred and re-ignited the behavior. Setbacks can be devastating for a person with IDD and their caretakers



## Core Concept 5: Danger & Safety

*"A person's ability to believe in and trust in a protective shield has been broken and must be restored."*

### For a person with IDD

Restoring trust requires both time and strategies which take the person's IDD into account.



### Say

- The 5th Core Concept for understanding traumatic stress responses in adults and families is: **Danger and safety are primary concerns in the lives of people who have had traumatic experiences.**
- Issues of danger, protection, and safety are paramount in dealing with adults and families who have had traumatic experiences. People 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 a person, parents, other caregivers, and community a significant amount of time to restore a sense of safety.
- Practical steps are essential to restoring safety and protection, but restoring confidence in a protective shield can take much longer. These concerns can affect ongoing perceptions of threat and behavioral responses often elicited by traumatic reminders.
- (Click the remote or press the space bar). **For a person with IDD:**
- In the aftermath of a traumatic experience, people and parents/caregivers alike want to have a protective shield against danger. Traumatic experiences challenge a person's & families' sense of a protective shield against danger, and restoring confidence in safety can take quite some time. Frequently, traumatic experiences threaten the ability to trust in the protective shield.
- The person with IDD is looking for caregivers to provide a protective shield.
- Families/caregivers may be looking for the community to provide a protective shield.
- During that time, the person & caregivers may be concerned about whether they will appropriately recognize future dangers, know what to do, and physically protect themselves.



## Facilitator Notes

### For Your Eyes Only

- Remind participants of the ecological model.
  - There is animation on this slide. You will have to initiate the animation for the slide content.
- Please be aware of when you will need to click the remote or press the space bar.

### Say

• The 6th Core Concept for understanding traumatic stress responses in people and families is: **Traumatic experiences affect the family and broader caregiving systems**

Caregiving systems are challenged in two interconnected ways.

- First, these systems are challenged by responding to the person's changes brought about by the person's traumatic experiences, losses, and adversities.
- Second, parents, other caregivers, family members, friends, and community members 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 a traumatized and bereaved person. Level of exposure, the extent of loss, frequency of reminders, and a cascade of adversities all affect the capacity of caregiving systems to function and meet their own needs and those of traumatized persons. It is essential to understand the types and amount of caregiving resources and how they have been affected.
- (Click the remote or press the space bar). We know that traumatic experiences affect the entire ecological system. We previously discussed how the larger ecological system affects the individual's response to trauma. Here we discuss how trauma may affect the larger ecological system, affecting a person's post-trauma response.
- (Click the remote or press the space bar). **For a person with IDD:**
- Parents/caregivers may feel devastated by what happened to the person with IDD. For example, caregiver effort into protecting him/her, and yet the traumatic experience still occurred. It also may be challenging to find trauma treatment and trauma-informed systems because their loved one has a disability
- The person, family, and caregiving systems may feel overwhelmed by the specific needs of that person and family, which are over and above the needs related to the person's IDD, affecting the sources of support that are made available.



## Core Concept 7: Protective Factors

*"Promoting and restoring."*

### For a person with IDD

Reassure the person and parents/caregivers that strategies for addressing the effects of traumatic experiences *can* be adapted for adults with IDD by enhancing protective factors.



VCU WITH

### For Your Eyes Only

*•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.*

#### **Say**

•The 7th Core Concept for understanding traumatic stress responses in adults with IDD 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 affected person brings intrinsic qualities (e.g., temperament) to their efforts to adjust and adapt. An anxious person may too quickly jump to catastrophic thoughts in the face of a reminder and have difficulties accepting reassuring information, whereas another person may seek and use outside support to calm himself or herself. Individuals may draw upon prior successes in adapting to hardship.

•Protective factors are also external to the person. For example, while it may take time to restore confidence in a protective shield, appropriate and timely protective steps can often be taken to protect against future dangers essential to addressing a person's concerns. With an enhanced sense of safety and security, people can benefit more from a host of promotive factors.

•**Promotive factors** are inherent resources in the person and within the person's physical environment that help propel a person towards a 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 person. People thrive in enriching learning and dynamic environments with stable and engaged caregivers, friends, and mentors. Replenishing and reinforcing the external resources helps people cope with their post-traumatic and grief reactions to handle adversities and reinvest in their developmental progression.

• (Click the remote or press the space bar). **For a person with IDD:**

•People with IDD may already be experiencing multiple adversities related to IDD. The person and parents/caregivers may feel that protective factors have been spent buffering the effects of the IDD. Providers' reassurance that strategies for addressing traumatic experiences *can* be adapted for adults with IDD by enhancing protective factors is essential.

•Adults with IDD may be limited in their ability to seek support when needed, make their needs known, and have others take protective action on their behalf. These are all protective factors that are potentially less immediately available to some adults with IDD. Providers can work with parents/caregivers to enhance attachment and create a safe and healing environment.



## Core Concept 8: Development

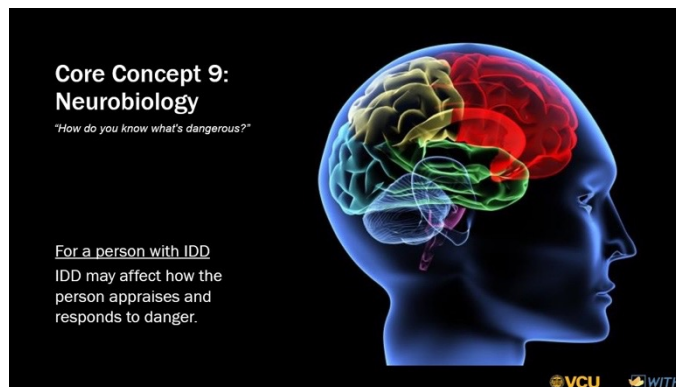
*"Don't just think symptoms—think development."*

For a person with IDD  
Traumatic experiences may result in a significant setback in developmental progress, which was already challenged by IDD.



### Say

- The 8th Core Concept for understanding traumatic stress responses in adults and families is: **Trauma and posttrauma adversities can strongly influence development.**
- Development represents a complex process of acquiring competencies and attaining achievements that unfold across multiple domains over time.
- Traumatic events and outcomes put important developmental areas at risk as a person matures through childhood into adolescence and then adulthood. Traumatic experiences have significant variability and can cause developmental interruptions, delays, cessations, regression, and precocious developmental acceleration.
- According to a person's current developmental level and developmental level at the time of the trauma, adults with IDD may have concerns about separation and attachment, psychosexual issues, physical appearance and injury, peer acceptance or rejection, and implications for their future.
- It is essential to understand how trauma experienced in childhood may have affected the development of an adult with IDD and how that influences their everyday experience.
- (Click the remote or press the space bar). **For a person with IDD:** •Traumatic experiences may result in a significant setback in developmental progress, which IDD already challenged.



### **Say**

•The 9th Core Concept for understanding traumatic stress responses in adults with IDD is: **Developmental neurobiology underlies a person’s reactions to traumatic experiences.**

•The brain is active and takes in information from the world around us, alerting us to danger, and calculates the actions to take in response.

•A person’s capacity to appraise and respond to danger is linked to evolving neurobiology that consists of brain structures, neurophysiological pathways, neural circuits, and neuroendocrine systems.

•Beyond flight or fight, the human brain is a social brain when it comes to danger, trauma, and loss. The brain seeks prevention, protection, effective intervention, and rescue, for example, by evoking and responding to cries of distress. The brain strives 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 to help achieve successive developmental tasks. At any point in time, trauma can cause changes in neurobiology that can affect a person’s capacities to negotiate the world around them, function at their best, and move forward in their development. It is essential to understand how adaptive responses can become maladaptive responses over time and adversely affect relationships, behavior, and health.

• (Click the remote or press the space bar). **For a person with IDD:**

•Neuromotor & physical aspects of IDD may affect how a person appraises & responds to danger.

•Some of the development of the nervous system responsible for appraising and responding to danger may not be as advanced in adults with IDD. Additionally, a traumatic experience can further affect maturation.

•At the same time, problems like sleep disturbances may compromise daytime attention and functioning.

Again understanding the developmental perspective of the person helps to determine the potential impacts.

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



### **Say**

•The 10th Core Concept for understanding traumatic stress responses in people with IDD is: **Culture is closely interwoven with traumatic experiences, response, and recovery.**

•Considerations of culture are essential to understanding all of the Core Concepts. People with IDD and their family/caregivers must be understood from the vantage point of multiple cultural influences, whether the society, their local community, specific group affiliations, or that of their family. Culture shapes meanings, beliefs, and expectations that govern attitudes, norms, behaviors, and social interactions.

•Culture can be used as a lens for understanding how a person and their family experience and express distress, disclose personal information, exchange support, and seek help.

•Culture is used to navigate life's challenges, including interpreting danger, protection, and safety, considering the personal consequence of a traumatic experience, and pursuing recovery paths. 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.

• (Click the remote or press the space bar). **For a person with IDD:**

•A person with IDD and their family is often part of multiple cultural identities and communities, including disability communities. All of these cultural identities are important to understand as part of the person's response to what happened and recognize strengths and sources of support.



•It is essential to recognize that sometimes cultural values and beliefs are congruent with our own, and other times they are not.

## Core Concept 11: Social Contract

*"Protection has failed in some way."*

**For a person with IDD**

People with IDD and their families are impacted by societal attitudes about disability, which can affect their capacity to obtain support and/or justice in the face of traumatic experiences.

### **For Your Eyes Only:**

- *There is animation on this slide. You will have to initiate the animation for the slide content. Please be aware of when you will need to click the remote or press the space bar.*

### **Say**

- The 11th Core Concept for understanding traumatic stress responses in people with IDD is: **Challenges to the social contract, including legal and ethical issues, affect trauma response and recovery.**
- Laws and regulations govern society to ensure safety and protection. Social institutions such as law enforcement, judicial systems, adult service systems, disaster preparedness and response agencies are integral to upholding the social contract.
- Because traumatic stress involves a failure or violation of the protective shield for people with disabilities, there is an inseparable link to the broader social contract. Whether one is speaking about 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.
- It is common for traumatized people and their families to interface with one or more of these social institutions. These interactions can make a strong impression on the person.
- The nature of these interactions and their response to them is critical to understanding the overall circumstances surrounding traumatic experiences or loss.
- A person with IDD's understanding of the social contract and the role of social institutions undergoes its developmental course and may need to be re-visited over time as it affects the person'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 person with IDD:**

- The report of a traumatic experience by a person with IDD may not be believed.
- Adults with IDD and their families may encounter the false belief that people with IDD cannot or do not experience trauma.
- Families often have had to deal with many social agencies and schools to obtain services to meet their family member's IDD needs.
- People 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 society's roles and responsibilities, already challenged by IDD, may be compounded by traumatic experiences.
- (Click the remote or press the space bar). *The community affects the ecological model. How do a community's values and broader society view disability? How does it affect their ability to seek support and justice?*

## Core Concept 12: Provider Distress

*"We are stewards not just of those who allow us into their lives, but of our own capacity to be helpful."*

For a parent/caregiver or provider of an adult with IDD

Traumatic experiences may (re-)evoke concerns about the vulnerability of the person with IDD and their own inability to protect them from harm.



### For Your Eyes Only

•Remind participants of the ecological model. The provider is embedded in a system with the person and family, and therefore may experience many aspects of what the person and family experience.

### Say

•The 12th Core Concept for understanding traumatic stress responses in adults with IDD is: **Working with trauma-exposed people can be extremely rewarding. However, this work can also evoke distress in providers for professional and personal reasons.**

•Providers must confront disturbing situations involving the person 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 person has to say. They are privy to some of the most intense, horrific, and difficult experiences. This can be emotionally demanding and challenging.

•From an individual to an organizational level, it is essential to ensure a sense of professional accomplishment rather than induce a sense of futility; bolster self-care that prevents emotional exhaustion, and receive organizational support that values the work and addresses the many practical issues that otherwise can cause severe professional distress.

•Working with traumatized people can evoke personal memories of trauma and loss-related experiences that must be adequately attended to and respected.

•Any individual who works directly with traumatized people is vulnerable to the effects of trauma referred to as secondary traumatic stress or compassion fatigue ( i.e., physically, mentally, or emotionally worn out, or feeling overwhelmed).

•Practicing self-care requires an active effort on the part of a clinician or service provider. Strategies for self-care include psychoeducation, clinical supervision, ongoing skills training, and self-care groups, evaluating secondary stress, caseload adjustments, and referrals to outside sources of help.

• (Click the remote or press the space bar). **For a parent/caregiver or provider of an adult with IDD:**

•Traumatic events may re-evoke their concerns about the person's vulnerability with IDD they support and their inability to protect the person from harm.

•For providers, hearing about a person's traumatic experience and coping with responses may evoke strong personal memories & feelings for caregivers and providers, as well.

• We will talk more about this in Module 6 when we discuss ways to promote provider self-care.

**Activity –**  
*Putting It Into Practice—*  
*Case Vignettes:*  
*Responses to Traumatic*  
*Experiences*



**For Your Eyes Only**

*This slide is a Group Activity.*

**Say**

We are going to return to our case vignettes to discuss how the 12 Core Concepts might apply to an adult with IDD who may have experienced trauma.

*[Advance to next slide.]*



**Facilitator Note:**  
**For Your Eyes Only**

•This slide is a Group 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 **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.

Say

Read the case vignette assigned to your table and then complete the **Putting Into Practice** handout referring to the 12 Core Concepts handout to help you identify which Core Concept may be at play for this person. [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.]

\_\_\_\_\_

- Identify the traumatic experience(s) and any trauma/loss reminders.
- Identify the Core Concepts that are applicable to the case.
- Think about the person with intellectual and developmental disability that you identified in our first exercise on the Making the Connection handout—how do traumatic experiences impact this person? How would you apply the Core Concepts to this person?



# 12 Core Concepts

## for Understanding Traumatic Stress in People with Intellectual and Developmental Disabilities

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**Core Concept 1: Complexity** - “There’s a lot going on in the person’s mind and body.”

**Core Concept 2: Life Experience** - “What the person brings to the experience from within and from the outside world effects their response.”

**Core Concept 3: Reminders & Adversities** - “What’s the world like that the person is living in afterwards?”

**Core Concept 4: Wide-Ranging Reactions** - “A person’s reaction to traumatic events varies greatly.”

**Core Concept 5: Danger & Safety** - “A person’s ability to believe in and trust in a protective shield has been broken and must be restored.”

**Core Concept 6: Caregiving Systems** - “Everyone is shaken up by what happened.”

**Core Concept 7: Protective Factors** - “Promoting and restoring”

**Core Concept 8: Development** - “Don’t just think symptoms—think development.”

**Core Concept 9: Neurobiology** - “How do you know what’s dangerous?”

**Core Concept 10: Culture** - “Culture is layered in its meaning and layered in its effects.”

**Core Concept 11: Social Contract** - “Protection has failed in some way.”

**Core Concept 12: Provider Distress** - “We are stewards not just of those who allow us into their lives, but of our own capacity to be helpful.”

### ! Essential Messages

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



### Facilitator Notes

#### Say

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 adults with IDD regain their sense of safety, value and quality of life.

## What Can a Provider Do?

- Learn about a person's moment-to-moment reactions during a traumatic event.
- Learn about their intrinsic and extrinsic factors that comprise the ecology within which the trauma occurred.
- Ask about trauma reminders.
- Ask how their perceptions of danger and safety may have changed following the traumatic experience.
- Explore how the cultural background of the person and caregivers may be influencing responses to the traumatic experience.
- Ask if they are involved with social institutions.



## Facilitator Notes

### Say

Here are some things that you as a provider can do to address the concepts that we discussed in Module 3. 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.

- Learn about a person's moment-to-moment reactions during a traumatic event.
- Learn about their intrinsic and extrinsic factors that comprise the ecology within which the trauma occurred.
- Ask about trauma reminders.
- Ask how their perceptions of danger and safety may have changed following the traumatic experience.
- Explore how the cultural background of the person and caregivers may be influencing responses to the traumatic experience.
- Ask if they are involved with social institutions.

## Activity – Action Planning

Essential Message 5



### **For Your Eyes Only**

*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.*

### **Say**

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 activity is done ask 2-3 people to share one strategy they think they would like to implement starting tomorrow.]*

# ACTION PLANNING

## ESSENTIAL MESSAGE 5

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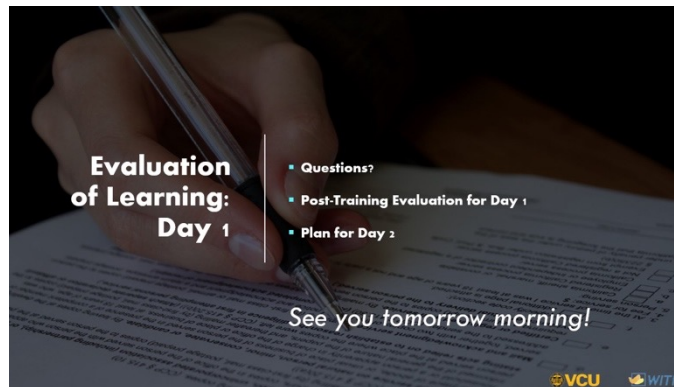
Think about the person you identified at the end of Module 1 that connects you to this work. What can help that person and other adults with IDD who have experienced trauma? (Put an “X” in up to 3 boxes next to the ideas you think you would MOST like to emphasize in your daily practice.)

### 5

#### ESSENTIAL MESSAGE 5

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

- ☐ Over the next 3 months, I will identify the **moment-to-moment reactions** people have during traumatic experiences with 3 adults with IDD.
- ☐ Over the next 3 months, I will explore **extrinsic factors** (e.g., physical environment, community & cultural responses to trauma & IDD) for 3 adults with IDD who have experienced trauma.
- ☐ Over the next 3 months, I will identify 2 **trauma reminders** for 3 adults with IDD who had experienced trauma. I will check in with them about their responses to these reminders each time I meet with them.
- ☐ Over the next 3 months, I will identify the impact of the traumatic experience on the **caregiving system** for 3 adults with IDD who have experienced trauma.
- ☐ Over the next 3 months, I will identify at least 3 **protective factors** that will help people to recover more quickly from the harmful effects of trauma or loss for 3 adults with IDD who had traumatic experiences. I will check in about these protective factors each time I meet with them.
- ☐ Over the next 3 months, I will ask 3 parents/caregivers about their feelings about the traumatic experience of the person with IDD they support to assess whether they need a referral to address **secondary traumatic stress**.
- ☐ (**Write my own.**) Over the next 3 months, I will...



### **For Your Eyes Only**

- This evaluation of learning will be completed at the end of Day 1 & Day 2.
- 

### **Say**

- 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!

# Module Four

Well-Being and Resilience







### Say

- In the last Module, we learned about how traumatic experiences affect development generally, and adults with IDD specifically,
- This Module, will help you understand the role of protective factors, such as a secure attachment and a healing protective environment, in enhancing well-being and resilience, and how to provide practical tools and support for people with IDD and their caregivers.

## Module Four: Learning objectives

What Will I Learn Today?

1. Explore the impact on caregivers of learning about the traumatic experience of the person with IDD they care for.
2. Explain strategies for strengthening protective factors to enhance 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 adults with IDD.
4. Identify person-centered planning techniques to help adults with IDD realize their hopes and dreams.



### **Say**

After completing module 4, you should be able to do the following:

1. Explore the impact on caregivers of learning about the traumatic experience.
2. Explain strategies for strengthening protective factors to enhance well-being, resilience, and recovery.
3. Describe frameworks for promoting a healing and protective environment to create a safe and meaningful life for adults with IDD.
4. Implement person-centered planning techniques to help adults with IDD realize their hopes and dreams.

## Self Care

- Step out and take a break.
- Talk to someone you trust.
- Do something relaxing.



### Say

- As in our previous Module, the topics we will cover may be upsetting to some of you. They may bring up difficult memories of clients that you have helped. It may evoke feelings of unfairness and injustice and enhances our desire to protect.
- 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 during this training and in your work setting. We will talk more about the importance of self-care in Module Six.



### **For Your Eyes Only**

- Remind participants of the risk/protective factors & ecological frameworks that we introduced in Module 1.

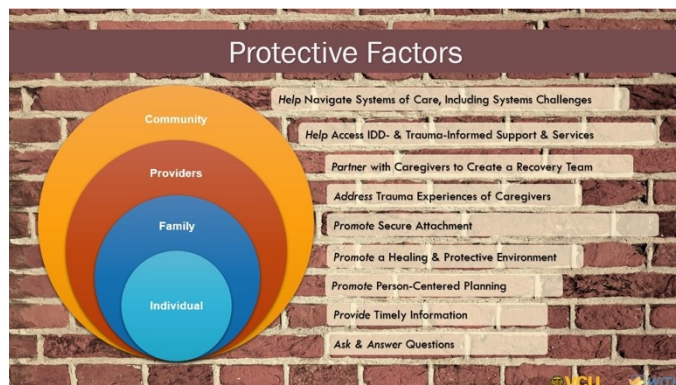
••

### **Say**

- Remember our brick wall? Let us take a closer look at the actual bricks.
- A key question is how do we *increase and enhance* protective factors? How do you add mortar to the bricks?
- Let us look at four specific areas where we can strengthen protective factors:
- Individual
- Family
- Community
- And Culture

What are ideas for increasing and enhancing protective factors in each of the four areas: individual, family, community, and culture?

- For example, one way to increase protective factors (community) is by educating the community about trauma and the value of including people with IDD in services, support, and treatment.



## Facilitator Notes

### For Your Eyes Only

- *There is animation on this slide. You will have to initiate the animation for the slide content. Please be aware of when you will need to click the remote or press the space bar.*

### Say

• Click the remote or press the space bar). These are examples of actions or the "mortar" to help strengthen protective factors or bricks:

- **Ask & answer** the person's and caregivers' questions
- **Provide** timely information
- **Promote** person-centered planning
- **Promote** a healing & protective environment
- **Promote** secure attachment
- **Address** traumatic experiences of caregivers, providers, and friends
- **Partner** with caregivers to create a recovery team
- **Help** the person and caregivers access IDD- & trauma-informed support & services
- **Help** caregivers navigate systems of care, including systems challenges

Protective factors can offset many challenges. As providers, your job is to help strengthen protective factors with specific strategies. We can think of the mortar as what strengthens protective factors—for example, *building* strong social connections, *promoting* person-centered planning, and *helping* caregivers navigate care systems.

## Respond

Change behaviors, policies, and services to take trauma into account



We will review some ways to respond in the aftermath of trauma. In the following two modules, we will discuss how providers can respond to an adult with IDD who has experienced trauma, avoid using policies and practices that might retraumatize them, and help them recover and thrive.

## Ask & Answer Questions

- Responses to Traumatic Experiences
- Cultural/Linguistic Factors
- Traumatic Experiences of Caregivers
- Family Dynamics
  - Current and historical dynamics
  - Needs of the Caregivers
- Existing Supports/Protective Factors



VCU WITH

## Say

The first place to start is to ask and answer questions

- People with IDD have concerns and questions after a traumatic experience. A provider can start by asking questions.
- Some people may feel reluctant to ask about trauma for fear of making things worse or stirring up emotions that they think the person cannot handle. Research has shown that people with IDD appreciate being asked about trauma – they feel like someone cares. When we do not ask about the trauma or how it has impacted the person, we may send the message that we do not care or they cannot handle it.
- Providers also need information about how the caregiving system is doing. What is the family environment like, and what was it like for them growing up? What is their current support system? The dynamics? How much support does the person have?
- And what questions do the family or other caregivers have?
- Recognize that caregivers' questions may center around what is to come. A vital role is to provide anticipatory guidance, especially related to how distress may be diminished and how traumatic experiences may affect the person 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 person still in the setting where the traumatic experience occurred? Does adult protective services need to be involved? Does the person need to be in out-of-home care?
  - How to protect the adult and still assure as much independence as possible?
  - Will the person, ever feel whole and secure again?
  - How can caregivers help the adult attain a valued and meaningful life, despite the traumatic experience?
  - How to obtain respite or home services?
  - How to maintain developmental progress?
- Ask participants to brainstorm about the kinds of questions caregivers may have. *[Allow participants 5 minutes to share ideas at their tables. Ask a few participants to share with the whole group.]*



### **Say**

• Efforts to provide early intervention for people with IDD should encompass broad, holistic approaches to support.

Psychological first aid is a strategy developed by the National Center for PTSD and the National Child Traumatic Stress Network. It emphasizes providing support and safety and helping connect trauma survivors with appropriate resources. Psychological First Aid is different from psychological debriefing, which has been shown to interfere with recovery. Unlike Psychological debriefing, Psychological First Aid does not assume that trauma survivors are doomed to develop PTSD and does not force survivors to talk about or process the trauma.

- Instead, Psychological First Aid focuses on using compassionate and supportive strategies to establish a sense of safety and stabilization, gather information on the immediate needs of the person (e.g., food, water, shelter), provide practical assistance in meeting those needs, help connect the person or family with social supports, provide information on coping strategies to reduce stress, and link collaborative services for more sustained monitoring and service delivery.

It may be helpful to supplement with in-home modeling and mentoring. This may sometimes provide more concentrated help than a treatment hour with a clinician. However, accessing these services may take additional coordination and support from the clinician and person's caregiving system.

### **Resources for learning Psychological First Aid:**

Johns Hopkins University and Coursera <https://www.coursera.org/learn/psychological-first-aid>

Red Cross <https://www.redcross.org/take-a-class/coronavirus-information/psychological-first-aid-online-course>

National Child Traumatic Stress Network:

<https://learn.nctsn.org/course/index.php?categoryid=11>





## Say

- For people with IDD who have experienced trauma, it is essential for providers and caregivers to create or recreate an interpersonal environment that is sufficiently healing to counteract the trauma.

- Following a traumatic experience, creating and maintaining consistent routines provide reassurance (e.g., return to regular routines as much as possible, providing additional support/reassurance if the person has new or worsened fears, limit exposure to media/other traumatic material).

People with IDD 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 person’s emotional state at the moment.

- Imagine it from the person’s perspective.

- Acknowledge it—reflect it through facial expressions and words (sad, scared, “you might be sad, I would be too...”)

- Gently comfort (“it will change,” “together we will get through it,” “it will get better”)

- Remember that “All behavior is communication” and recognize that a given behavior may be the person’s method for adapting to unwanted circumstances. Disentangling and understanding behavior and managing it can be challenging and overwhelming, particularly if the adult with IDD is engaging in trauma-related behaviors that others find challenging.

This requires providers and caregivers to imagine a person’s experience of trauma and recognize they are coping as best they can.

- Person-centered tools & interventions can create an environment that makes the behavior expression less challenging to understand and address.

- For people 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.

- We will briefly describe GT, PBS and Positive Identity Development principles later in this module. Gentle Teaching, PBS, and Positive Identity Development tools can be readily learned and used by caregivers and providers to promote and recreate that secure base. There is also more information about GT, PBS, and Positive Identity Development in the **Supplemental Materials** section.

## All Behavior is Communication



"If You Listen, You Will Hear Us" [https://youtu.be/Hp4PW17U\\_h8](https://youtu.be/Hp4PW17U_h8)

VCU WITH

### For Your Eyes Only

• **Optional Video.** A number of videos will be suggested for use throughout the training.

"If You Listen, You Will Hear Us" [https://youtu.be/Hp4PW17U\\_h8](https://youtu.be/Hp4PW17U_h8)

### Say

- This video reinforces how people with intellectual disabilities, including people with multiple and severe disabilities, communicate. This is an essential framework from positive behavioral supports. It provides examples of "micro-behaviors" and gentle teaching (which will be discussed later).
- A trauma-informed approach also recognizes that a person's behavior may reflect underlying trauma. We need to consider the possibility of trauma and strive to listen to what the person is trying to communicate to help them heal.

## Enhance Well-Being and Resilience

- Families and caregivers are a critical part of both protecting people from harm and enhancing their well-being.
- Providing trauma-informed education and services to parents and other caregivers enhances their protective capacities.
- Providers should recognize that caregivers themselves may have trauma histories or experience secondary traumatic stress.



VCU WITH

## **For Your Eyes Only**

- *There is animation on this slide. You will have to initiate the animation for the slide content. Please be aware of when you will need to click the remote or press the space bar.*

### **Say**

- How do we build up a wall of protective factors around adults with IDD who have experienced trauma?
- (Click the remote or press the space bar). Enhancing the family's well-being and resilience is an essential part of enhancing well-being, resilience, and recovery.
- Families are a critical part of both protecting people from harm and enhancing their natural resilience. However, caregivers may find it challenging to be protective if they have been affected by trauma, and they may need help and support to draw on their natural strengths.
- Additionally, in situations in which 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 enhance their protective capacities, increasing the resilience, safety, permanency, and well-being of the person with IDD.
- Providers should recognize that caregivers may have trauma histories or experience secondary traumatic stress and provide them with appropriate trauma-focused support and intervention.

### Recognize Caregivers' Hopes & Concerns

Caregivers of people with IDD want:

- To find & provide the best care for the person they support
- To sustain & maximize the person's maturity and independence across development & changing circumstances
- To help them function at his/her best and attain a meaningful life



### Say

- It is essential to keep in mind that safety & protection are chronic worries among caregivers about the person they support. So is the promise of the fullest, most valued life they can achieve. Both of these concerns and hopes are heightened in the parents of a child with IDD.
- Caregivers of people with IDD want:
- To find & provide the best care for the person they love and support
- To sustain & maximize their maturity and independence across development & changing circumstances
- To help them function at his/her best and attain a meaningful life

## The Challenge for Caregivers

- Feelings of Inadequacy/ Not Knowing What to Do
- Grief & Loss
- Strain on Relationships
- Anticipatory Anxiety
- Secondary Traumatic Stress
- Stress due to ongoing needs of the person that has continued into adulthood



## Facilitator Notes

### Say

- Providing care for another person, whether an adult child, a family member, can strain a relationship, even without IDD or trauma. The provider **may feel inadequate** because they do not know what to do.
- With IDD and trauma, caregivers may vary in their acceptance and feelings of grief and loss related to the IDD and trauma and how they respond. They may not fully understand the person's functional level 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 actual act of listening to the traumatic experiences of others and dealing with the aftermath of traumatic experiences, including their behavior, thinking, and emotional responses, may take an emotional toll that can compromise caregivers' functioning and interfere with limit-setting/routines and result in over-protection. Caregivers might also relax routines and limits because they feel the person has "suffered enough," which can be more unsettling.
- Providers should recognize the potential impact of traumatic experiences of people with IDD on their caregivers. Caregivers may have **anticipatory anxiety** about safety, protection, ensuring that the person they care for will be happy and healthy.
- They may also experience **secondary traumatic stress** due to hearing about the traumatic experience(s), their role in failing to protect, and because it is a reminder of their trauma history. For example, it is not unlikely that for many, the traumatic experience(s) involved both the person and the caregiver, and so they might serve as a traumatic reminder for each other. Intervention requires the reparation of the relationship, as this will be the recovery vehicle.
- Families of adults with IDD may have **increased stress due to the person's ongoing needs** that have stretched into adulthood.
- Providers can support caregivers by acknowledging sources of stress and concern (e.g., financial stress), providing anticipatory guidance, and answering questions.



### Address Traumatic Experiences of Caregivers

A personal history of trauma can:

- Compromise caregivers' decision-making
- Interfere with their ability to form and maintain secure & trusting relationships (with the person with IDD, partners, & service providers)
- Impair caregivers' ability to regulate their emotions
- Lead to less effective coping strategies, including substance abuse
- Cause caregivers to be reminded of their own traumatic experiences

### **Say**

- Review how a caregiver's personal history of trauma can impact his/her behavior. Caregivers' avoidance of trauma reminders can prevent them from seeing "red flags" regarding the person's safety or contribute to minimizing/denying the person's abuse experiences or maximizing/exaggerating their experiences.
- A parent/caregiver with his/her trauma history may have experienced firsthand how difficult and painful it is to talk about the trauma and may therefore want to "shield" the person they support from a similar experience.
- Caregivers of someone with IDD who have had a traumatic experience often have secondary traumatic stress reactions.
- Past and recent traumatic experiences can impact caregivers' ability to keep the person safe and work effectively with providers.
- Coordinating caregivers' care (mental health needs and trauma treatment) with a person's care (e.g., medical and trauma treatment) can pose challenges.
- When the parent is the source of the traumatic experience, it adds a layer to the dynamics of the relationship and how treatment needs to occur.
- The safety of the person with IDD in the relationship must be addressed first.
- Interventions will vary depending on whether the person is with the parent or out of the home (which often depends on the nature of the trauma). In such cases, specialized therapeutic interventions are typically warranted with the person, parent, and possibly the dyad, depending on the situation and plan for the family.



## Promote Secure Attachment

- A highly responsive caregiving style is associated with a variety of benefits across developmental stages – including into adulthood.
  - Imagine the inner life of the person
  - Create or re-create a nurturing/healing environment
  - Provide comfort to help a person regulate
  - Structure, routine & limit-setting
- Facilitate healthy relationships with peers in the community.

## Facilitator Notes

### Say

- Research on optimal child development shows that protective, nurturing, attuned, and responsive parenting serves as a "secure base" and supports resiliency through adulthood. Adults with IDD may still rely heavily on caregivers to provide a secure base.
- Several characteristics associated with developmental delays and disabilities may impact caregiver 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 caregivers' efforts to be responsive.
- Similarly, caregiver characteristics (unrelated to the person's disability) may affect caregiver responsiveness. If the caregiver is depressed, for example, responsiveness and resilience of the caregiver can be compromised, at least temporarily.
- Traumatic experiences can affect caregiver responsiveness because they can create more questions and hopelessness/helplessness in the face of many emotions (e.g., stress, loss, grief, anger).
- the caregiver's responses to the person need to be contingent and sensitive (i.e., accurate readings of the person's cues and needs, and empathic, supportive responses). A very engaged caregiver but misreading the person's cues (e.g., being overly intrusive) can also be problematic.
- Adults with IDD also need to have secure relationships with peers, with and without disabilities, in the community. Trauma may negatively impact their ability to judge between healthy and unhealthy relationships, and this may be an area in which they need additional support and skill-building.
  - As providers, our task is to provide or help caregivers provide a secure base (secure attachment) as a protective factor or re-create a secure base when damaged by trauma to help the person with IDD develop meaningful and healthy relationships.





### **Say**

•It is essential to identify local resources that are trauma-informed.

•**Informal Support** (e.g., community/church groups, extended family, friends, other families with people 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

•Disability services, waiver supports, Supplemental Security Income [SSI], in-home supportive services—providers can help the person with IDD, and their caregivers access support by advocating for them.

•Organizations that provide trauma-informed services.

#### •**Peer-to-peer Support**

•Organizations that connect families or connect self-advocates to other self-advocates

#### •**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 promote the issues important to them and their families.

It is 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.



## Activity – *Local Resources*



*This slide is a Group Activity. Have participants fill out the Local Resources handout. Participants should start by identifying five local organizations that they frequently refer families to or find helpful. Once they have created their list, participants should walk around the room and ask others to share their list—they should come up with five new organizations to add to their list. Consider collecting everyone's handout and making copies that could be compiled into a resource list distributed to everyone after the training.*

### **Say**

You should have a handout entitled **Local Resources**. Think of 5 local providers you regularly use to refer/assist your adults with IDD and their caregivers to help them access IDD- and trauma-informed services. Please 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 five new resources to add to your list. *[Allow participants 5-10 minutes to fill this out. Have one or two people share.]*

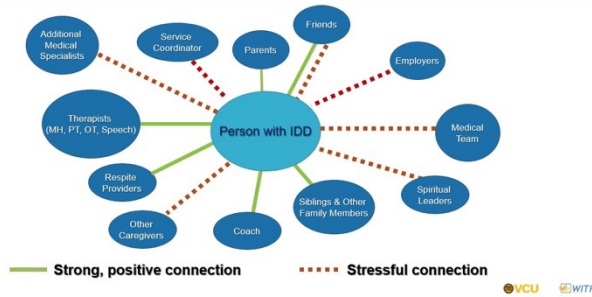
# LOCAL RESOURCES

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Begin this exercise by identifying 5 local organizations that you frequently refer people and their caregivers to, or find helpful. Once you've created your own list, walk around the room and ask others to share their list—find at least 5 new organizations to add to your list.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_
6. \_\_\_\_\_
7. \_\_\_\_\_
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10. \_\_\_\_\_

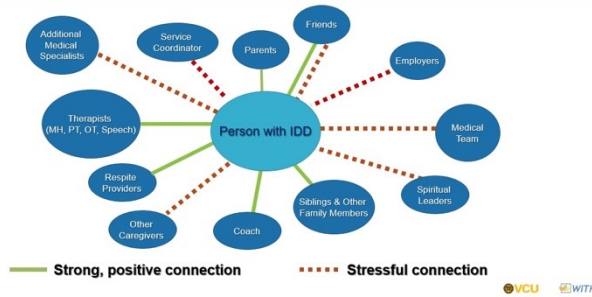
## Partner with Caregivers to Create a Recovery Team



### Say

- The team of people involved in a person's life can include:
- Day support providers, job coaches, employers, co-workers
- Parents and other caregivers and family members, such as siblings and extended family (grandparents)
- Friends & other informal support networks
- Medical professionals
- Mental health providers (e.g., psychologist, psychiatrist, social worker)
- Providers in other disability service systems (e.g., case managers, Regional Centers, federal programs)
- Respite providers
- It is essential 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 person's care, consisting of a person's treatment providers. In IDD culture, a team is used more to develop a support plan or service plan.

## Partner with Caregivers to Create a Recovery Team



Cont.

- By “recovery team,” we introduce the idea that people with IDD often have many providers in their lives (even before a traumatic experience). While we are not suggesting that providers must develop a formal “recovery team,” it is essential for providers to know who are the other professionals involved in the person’s care. Moreover, find out from the person with IDD or their caregivers they find most supportive and helpful.
- Ideally, every team member should be striving for the same goals: the person’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 people. **Some providers working with the person may have close, positive relationships with the person or their caregivers. Others may not be very active or engaged with a person. Still, others may be a source of conflict and stress. In creating a recovery team, it can be helpful to know the strength and quality of those connections.**
- It is unlikely that all providers that a person with IDD and family encounters will be equally trauma-informed. It is essential to know where there are gaps in trauma information so that providers can help caregivers create an effective trauma-informed recovery team.
  - Some team members may have trauma histories of their own or be experiencing secondary traumatic stress. Secondary traumatic stress refers to the emotional effects of close, constant contact with people who have experienced trauma, and we will talk more about this in Module 6.



### Help Adults and Caregivers Navigate Systems of Care

- Co-occurring Mental Health Diagnoses & Conditions
- Support Families Through Systems' Challenges
  - Appeals Process
  - Wait Times
  - Reimbursement Issues
- Understanding Medicaid, Managed Care, Affordable Care Act

### Say

- Many people with IDD have co-occurring developmental and mental health diagnoses and conditions, resulting in the use of multiple service systems.
- Involvement in multiple systems often means negotiating obstacles in systems. Sometimes the role of the provider is to help the person and their caregivers deal with the frustration and challenge of waitlists and lack of availability of formal supports, provide tools and ideas to help with uncertainty, and provide resources for what they can do while they wait.
- 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 the person's needs.
- There are many instances when needed services may be denied by insurance companies or public agencies who “ping-pong” the person back and forth to avoid covering care for the person 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 education of providers within those systems.

## Activity - Putting It Into Practice



This is an Activity Slide. There are two options for playing – card game and board game.

### Card Game Option

This option is a simple option for in-person workshops where participants are grouped into small groups. The cards can be printed on “business card” paper available at most office supply retailers. Print one set of cards per group.

This is an opportunity for workshop participants to practice identifying risk factors and promoting protective factors for people with IDD. This activity is especially valuable when groups are arranged in such a way that people from different disciplines and/or agencies are grouped together. If tables have not already been arranged in this way, take a few minutes and encourage participants to sort themselves into groups.

- Divide the deck into a deck of risk cards and a deck of protective cards. Deal 5 protective cards to each person.
- When it is your turn, draw a risk card and read it aloud.
- Everyone picks one of their protective cards that they think will best address the risk. The person whose turn it is then reads the possible solutions and picks their favorite and the group discusses the ideas.
- Everyone draws a new protective card to maintain 5 cards.

## Activity- Putting It Into Practice



[http://tiny.cc/THRIVING\\_boardgame](http://tiny.cc/THRIVING_boardgame)



This is an Activity Slide.

### Board Game Option

The board game option is ideal for Virtual Meetings. Split groups into their breakout rooms. One person will need to open the board game in their browser and share their screen. The person sharing their screen will need to control the board for everyone.

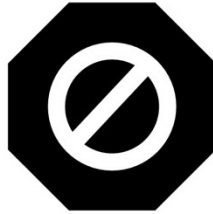
The board game can be found at:

[https://www.flippity.net/bg.php?k=IB3GxOaCP0R\\_LehvqRAXavnORTIOMuO3HFvK7moqinMM](https://www.flippity.net/bg.php?k=IB3GxOaCP0R_LehvqRAXavnORTIOMuO3HFvK7moqinMM)

Or [http://tiny.cc/THRIVING\\_boardgame](http://tiny.cc/THRIVING_boardgame)

## Resist

Take steps to resist re-traumatization of clients and staff with trauma histories



In this module, we discussed strategies that enhance wellbeing and resilience and ways to respond to trauma. Another critical factor in enhancing the wellbeing and resilience of adults with IDD and their caregivers is to avoid using policies and practices that might retraumatize people with IDD, their caregivers, and providers, such as restraints and seclusions, or behavior supports focused on compliance and control, and instead implement policies and practices to help them recover and thrive.



## Promote Person-Centered Planning

- Develop a treatment and support plan using child-centered planning
  - Identify what is important to the person
  - Identify what others need to do to support what is important to the person
- Identify key individuals involved in person's life
- Foster collaborative relationships among those individuals



### Say

Person-centered planning—provides a process for bringing a person and their caregiving team together to discuss the person's hopes and dreams. Person-centered planning is a strength-based process that is a celebration of the person and a mechanism of establishing the commitment of the team members to supporting the person's goals. It is about "listening" to the person no matter how he/she communicates and finding out what is important to them.

- A plan should integrate requirements and goals across agencies.
- This will be discussed in more detail in Module 5.

## Positive Behavior Support

- Effectively used with individuals with IDD & mental health needs
- Different from behavior management
- Starts with the premise that individuals are coping in the most effective way they know
- Change the environment so that individuals can get what they want & teach skills so they have more effective tools to get what they want or cope when they can't



### Say

- Positive behavior support (PBS) is a set of evidence-based strategies used to increase the 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 people 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 people are coping in the most effective way they know.
- The PBS approach is to change the environment to meet their needs and teach skills to support meeting their needs or coping when they cannot.



## Gentle Teaching

- Developed by John McGee to interact with people with IDD & challenging behavior.
- Basic premise is that challenging behavior is a reflection of life experience often characterized by absence of quality of life &/or trauma.
- Focuses on interacting in ways that improve quality of life for the person with IDD through meaningful & positive reciprocal relationships.
- Relationships are understood in GT as transacted in repetitive micro-behaviors using the tools of our hands, eyes, voice & presence.

<https://gentleteaching.com/>



## **For Your Eyes Only**

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

To learn more about Gentle Teaching: <https://gentleteaching.com/>

## **Say**

- The behaviors that contribute to developing a secure base that serves 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 for people with IDD with challenging behavior. It has since expanded as a practical approach for people with mental illness, older persons, and children, and it has grown an international following.
- Its basic premise is that challenging behavior reflects life experience often characterized by the absence of quality of life and trauma.
- It focuses on how supporters can interact in ways that improve the person's quality of life 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 caregivers as well as providers to communicate:
  - "You are safe with me."
  - "It is good to be with me." • "It is good to be loved and be loving."

## Gentle Teaching



This video shares a discussion of Gentle Teaching's central purpose. <https://youtu.be/lwiPBj7ukvc>

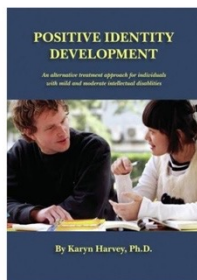
Other recommended videos:

Gentle Teaching: <https://youtu.be/NpWjKxcmXsl>

An interview with Dr. Karyn Harvey about trauma-informed supports and Gentle Teaching: <https://youtu.be/A6CTUUMz7zo>

### Positive Identity Development

- Developed by Karyn Harvey, PhD to assist individuals with IDD in revealing their true potential as human beings & experiencing the happiness in life that they so deserve
- Positive identity development for people with IDD focuses on discovering, defining & celebrating the self vs taking on the sole identity of “disabled”
- Basic premise is that an approach modeled on psychological well-being vs ineffective behaviors leads to human health & authentic happiness



VCU WITH

### Say

•Positive identity development and happiness levels have been introduced by Karyn Harvey, Ph.D., as an effective way to promote healing. In her book, Positive Identity Development, understanding happiness levels provide markers that can 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 people with IDD focuses on discovering, defining & celebrating the self vs. taking on the sole identity of the “disabled.” People with IDD not only often see themselves as disabled, but also...
- The “bad” one (due to behaviors).
- The dumb one.
- The one who cannot read.
- The one who talks funny.
- The one who cannot ride a bike.
- The one who cannot drive a car.
- The one who cannot!
- Premise of positive identity development is focusing on psychological well-being vs. maladaptive behaviors leads to human health & authentic happiness

### Positive Identity Development

- **Pleasure:** things we enjoy in a predominantly happy state (e.g., eating, watching TV)
  - Passive
- **Engagement:** actively participating in something that is enjoyable (e.g., cooking, hiking)
  - Often leads to the development of skills & talents
- **Meaning:** the act of making a real difference in the world of others through use of one's own strengths



<http://www.pursuit-of-happiness.org/teaching-resources/>

VCU WITH

### Say

• In Positive Identity Development, Dr. Harvey identifies happiness levels as key to determining behavioral change & adjustment. Levels are based on the groundbreaking work of Dr. Martin Seligman. Dr. Seligman outlines three 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 lives, but people who get most of their leisure enjoyment from this passive pleasure level are more prone to depression.

• It is notable that often primary reinforcers/rewards used in behavioral programs are at this level

• **Engagement:** 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 skills & strengths

• **Meaning: the act of making a real difference in the world of others through using one's 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 people, people with IDD also benefit more from engagement than pleasure, and most from meaning & purpose.

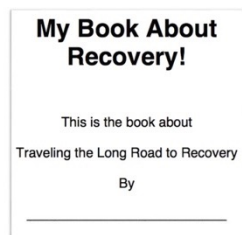
Remember Maslow's Hierarchy of Need that we discussed in Module 1? Helping people with IDD, especially those who have experienced trauma, develop a positive identity through engagement and meaning-making so that they can move beyond safety to developing a sense of love and belonging, self-esteem, and self-actualization.

• For more information and resources, visit Martin Seligman's website: <http://www.pursuit-of-happiness.org/teaching-resources/>

## Positive Identity Development

Materials accompany *Positive Identity Development: An Alternative Treatment Approach for Individuals with Mild and Moderate Intellectual Disabilities* (Harvey, 2009)

Available at [pid.thenadd.org](http://pid.thenadd.org)



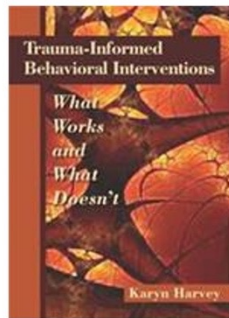
## Say

- Dr. Harvey 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/>.

## Trauma-Informed Behavioral Interventions

- Rich descriptions and case vignettes of effects of trauma on people with IDD.
- Strategies for trauma-informed crisis prevention and intervention.
- Examples of trauma-informed behavior support plans

<https://www.aaid.org/publications/bookstore-home/product-listing/trauma-informed-behavioral-interventions-what-works-and-what-doesnot>



This book by Dr. Karyn Harvey, author of the Positive Identity Development book is an excellent resources for providers who are involved in creating and using person-centered plans, behavior support plans, and/or mental health plans.

The recommendations in this book are consistent with the model of trauma-informed and trauma-sensitive interventions. The plans aren't necessarily geared to *treat* post-traumatic stress disorder symptoms directly, the way a more trauma-specific treatment would (which we will discuss next). But, they are designed to help identify supports needed to help the person feel safe, supported, and in control, which are necessary conditions for recovery from trauma. This book guides the support team in recognizing a person's trauma history, considering their unique manifestation of traumatic stress symptoms, and how to create positive person-centered support plans that take that trauma into account and help the person heal.

Dr. Harvey has a 2-hour presentation on Trauma-Informed Behavioral Planning available on youtube that may be of interest to participants to continue their education:

<https://youtu.be/xatOcqtfttl>



### Essential Messages

6. Utilize an IDD- & trauma-informed person-centered approach to support both the adult with IDD & the caregivers.

7. Help caregivers, and other professionals in the person's life, strengthen protective factors.



### Say

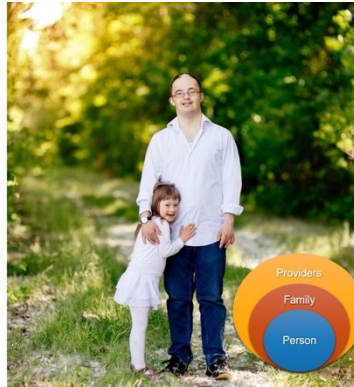
- As a recap, let's review the Essential Messages that we just discussed in Module 4.

6. Utilize an IDD- and trauma-informed person-centered approach to support both the adult with IDD and the family.

7. Help caregivers, and other professionals in the person's life, strengthen protective factors.

## What Can a Provider Do?

- Identify and enhance strengths and natural supports.
- Ask questions about what they need.
- Take the time to listen to and ask them what about their questions, concerns & challenges.
- Provide practical tools for promoting a secure attachment and a healing & protective environment.
- Provide anticipatory guidance.
- Help access support.
- Help find access to respite care.



## Say

• Here are some things that you as a provider can do to address the concepts that we discussed in Module 4.

- Identify and enhance strengths and natural supports.
- Ask about the trauma and what they need.
- Take the time to listen to and ask them what about their questions, concerns & challenges.
- Provide practical tools for promoting a secure attachment and a healing & protective environment.
- Provide anticipatory guidance.
- Help access support.
- Help find access to respite care.

## Activity – Action Planning

Essential Messages 6 & 7



### **For Your Eyes Only**

*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.*

### **Say**

Pull out your handout titled, **Action Planning: Essential Messages 6 and 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 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 activity is done ask 2-3 people to share one strategy they think they would like to implement starting tomorrow.]*

# ACTION PLANNING

## ESSENTIAL MESSAGES 6 & 7

---

Think about the person you identified at the end of Module 1 that connects you to this work. What can help that person and other adults with IDD who have experienced trauma? (Put an “X” in up to 3 boxes next to the ideas you think you would MOST like to emphasize in your daily practice.)

### 6

#### ESSENTIAL MESSAGE 6

Utilize an IDD- & trauma-informed person-centered approach to support both the adult and the caregivers.

- ☐ Over the next 3 months, I will identify at least 3 **activities** that adults with IDD who have had traumatic experiences find meaningful. I will check in with them about these activities each time we meet.
- ☐ Over the next 3 months, I will identify at least 3 **life goals** (in their own words), that adults with IDD who have had traumatic experiences have for themselves. I will check in about these life goals each time we meet.
- ☐ Over the next 3 months, I will identify at least 3 adults with IDD who have **siblings**. I will work with the caregivers to identify needs of the siblings.

### 7

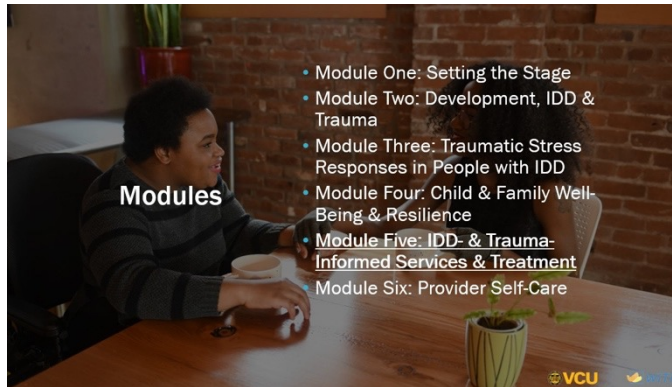
#### ESSENTIAL MESSAGE 7

Utilize a developmental lens when making meaning of a person’s traumatic experiences and responses.

- ☐ Over the next 3 months, I will identify 3 **protective factors** to strengthen for 3 adults with IDD who had traumatic experiences. For each person, I will review these protective factors each time we meet during this 3-month period and develop strategies for enhancing them.
- ☐ Over the next 3 months, I will identify 3 adults with IDD, with whom I can work to **increase happiness** through activities that provide engagement and meaning. I will ask them about the activities each time we meet.
- ☐ Over the next 3 months, I will identify 3 adults with IDD to work with on building a **recovery team**. I will identify ways (in person, by phone, or by email) that I can help facilitate the participation of other providers on the recovery team.
- ☐ (Write my own.) Over the next 3 months, I will...

# Module Five

IDD- and Trauma-Informed Services and Treatment



### **Say**

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

Photo attribution: <https://affecttheverb.com/disabledandhere/>

## Module Five: Learning objectives

### What Will I Learn Today?

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



### Say

- After completing today's training, you should be able to do the following:
  - 1.Explain how to enhance protective factors of people with IDD & caregivers 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 people with IDD.
  - 3.Discuss strategies for adapting the core components of trauma-informed treatments for people with IDD.
  - 4.Identify strategies for partnering with agencies & cross-system collaboration.

## Multiple Providers, Multiple Hats

Sometimes a provider has multiple roles. Most of the time, multiple providers each wear multiple hats.



### Say

- It's important for providers to know the full range of services (both IDD and trauma) that a person with IDD may need so that he/she can make appropriate referrals when necessary and help caregivers 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 people with IDD and their caregivers 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?





The diagnostic complexity of IDD and trauma often results in the involvement of 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. Is it a

- Known trauma
- Suspected trauma
- Unsuspected trauma/unidentified trauma, which may present as a behavioral challenge.

A strategy is needed to address this diagnostic complexity, which is interdisciplinary in nature and optimizes referral of the person with IDD who is presenting with symptoms of trauma.

Let's talk about an example of how a person with IDD and trauma may be identified and the various service systems they may encounter along the way:

- **Natural/Informal family supports.** Families or care providers notice that a change in mood, functioning, or behavior has occurred and they reach out to formal and informal supports for information and resources.
- **Primary Care Provider** (General Practitioners, Advanced Nurse Practitioners and Physician Assistants) for initial history and physical examination, preliminary screening. Primary care providers hold a unique position in often being the first and frequent point of contact with the health care system for an adult with IDD. 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.

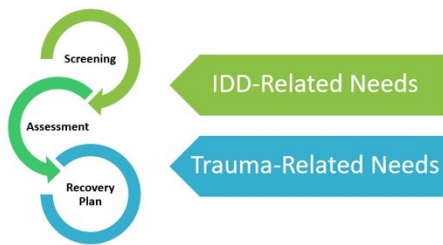


Cont.

- **Adult Protective Services:** The primary care provider may decide that involvement of Adult Protective Services and Law Enforcement Agencies is indicated. **You do not have to wait for a referral from a Primary Care Provider to involve Adult Protective Services or law enforcement.** A suspicion of abuse or neglect is all that is needed to make a report. It is the job of these agencies to assess and investigate. Many states have laws on mandated reporting of suspected abuse, neglect, or exploitation of adults with IDD.
- **Crisis Support Services:** Many states have crisis support services for people with IDD through regional Department of Developmental Services (varies by State) to provide or coordinate services and supports for individuals with DD experiencing mental health or behavioral crisis. 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.
- **Referral to Trauma-Focused Therapy:** Ideally, the discovery of trauma and associated mental health or behavioral concerns would result in referral to trauma-focused therapy that is appropriate/adapted to person's intellectual level (Psychology, Social Work, involvement of Occupational Therapy and Physical Therapy as needed to help the person participate in therapy).
- **Referral to informal support or advocacy groups** to help the person or their caregivers cope with and constructively address challenging or disruptive behaviors related to traumatic experiences (panic attacks, frequent masturbation, self- injury, lack of socialization). As we've discussed, not everyone who experiences trauma will require formal trauma-focused therapy. As we discussed in the last module, they may benefit from increased social supports through local self-advocacy groups or community engagement.

What is the strategy for referring adults with IDD with known, suspected, or potential unidentified trauma at your organization?

## Developing a Recovery Plan



There is no one-size-fits-all approach to treatment for people with IDD. To effectively meet the needs of people with IDD who have experienced trauma, we need to identify where they are at in terms of both IDD-related needs and trauma-symptoms.

(Click the remote or press the space bar). **Screening** is often the first step. These are typically less formal assessments, and may require minimal training to administer. They may be questionnaires or brief interviews. Screening instruments are typically designed to be very sensitive to picking up symptoms, but not very specific. This means that screening instruments will tend to have high true positives and a fairly high level of false positives. The purpose of screening is to “cast a wide net” and identify people who are likely to need further assessment because it is better to further evaluate someone who doesn’t need services than to miss someone who does.

(Click the remote or press the space bar). **Assessments** are more formal and in-depth. They are typically conducted by someone with expertise or credentials in a specific field, such as a psychologist. The purpose of assessments are to collect more detailed information and zero-in on a diagnosis.

(Click the remote or press the space bar). The purpose of screening and assessments is to facilitate the development of an appropriate **Recovery plan**, which may include a treatment plan, service plan, or support plan depending on the needs of the person and the service delivery system.

Remember that not all people who experience a trauma will need treatment. In fact many, if not most, will be resilient with the sufficient protective factors in place. And not all of those who will need treatment will have posttraumatic stress disorder. As we discussed in Module 3, there are a range of traumatic stress reactions. A full assessment will help to determine whether treatment is needed, and what kind.

## Identify IDD-Related Support Needs



- Developmental assessment & screening provide care providers with the opportunity to
  - Understand how the person is functioning
  - Understand how treatment may need to be modified to support the person
- Input from caregivers is invaluable in understanding the person's functioning in relation to his/her peers



### **Say**

Identifying a person's IDD-related support needs is essential for determining the kinds of accommodations that may be necessary to develop a recovery plan. For adults with IDD, they may have undergone psychological testing in childhood and it may be possible to request records from their healthcare provider or school system. If these records aren't available or are out-of-date, it may be helpful to conduct a new screening and assessment.

The role of the provider when meeting a person with IDD is to understand how the person is currently functioning and how their level of functioning may have been impacted by the trauma. There are standardized screening and assessment tools for this, but information from caregivers is invaluable in this process as they are often making comparisons between the person and his/her peers constantly. They have a wealth of knowledge about how the person is functioning and a good sense of their developmental stage and how that may compare to expectations given the person's chronological age.

## Identify IDD-Related Support Needs



### Say

There are many screening tools available, each with its own set of strengths and weakness, and each with its specific applications. We won't go into depth on the screening tools that are available but we will mention a couple that may help in identifying a person's functioning and readiness for participating in their recovery plan.

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 World Health Organization Disability Assessment Schedule 2.0 are free to use and may be helpful as a starting point in obtaining information from individuals and caregivers.

• **THE WHODAS 2.0** is a **screening instrument** which means that it is not developed to provide an indepth assessment of the person's abilities or functioning. It was developed to be compatible with the ICD-10 and the DSM-5 for determining a person's level of adaptive functioning. It includes multiple versions depending time and level of detail needed.

## Identify IDD-Related Support Needs



- The Arc's Self-Determination Scale Adult Version
- Right of people to have control in their lives.
- Original Version
  - <https://thearc.org/wp-content/uploads/forchapters/SD%20Scale%20Procedural%20Guidelines.pdf>
- Adult Version
  - <https://rtcom.umn.edu/database/instruments/asds>



### **Say**

Another screening assessment that may be helpful in designing the recovery plan is the Arc's Self-Determination Scale. This scale was developed to assess individual strengths and weaknesses in self-determination and facilitate the person's involvement in planning educational and treatment strategies.

Self-Determination is the right of people to have control in their lives. Too often people with IDD are not given sufficient opportunities to make meaningful decisions in their lives, and this includes the right to make decisions about their behavioral and mental health care. Further, people who have experienced trauma often feel a loss of control. Re-establishing a sense of control can help to re-establish a sense of safety and promote healing. Therefore, it is important that providers facilitate self-determination as much as possible in the aftermath of trauma.

The Arc's Self Determination Scale has two versions. The original version was designed for students and young adults to assess and encourage participation in their educational and career choices. It was developed and normed on a primarily adult sample, although many questions refer to teachers, which may not apply to many adults with IDD. The Adult Version includes scales measuring Choice and Control, Community Inclusion, Holistic Health and Functioning, and Person-Centered Planning and Coordination.

## Identify IDD-Related Support Needs



### Say

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 may have occurred in many different service systems, from the pediatrician's office during a well child visit, to schools, Regional Centers, or neuropsychological or psychoeducational assessment from a mental health provider. Some may be identified by the courts or legal system following an offense. Some individuals with borderline or mild impairment may not be identified until much later in life, particularly in poor and underserved populations, so the absence of childhood diagnosis does not mean that IDD is not present.

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 people with IDD and families may have to go through many different "doorways" to try to find appropriate services.

## Identify IDD-Related Support Needs



- Examples of Assessment Tools
  - Intelligence assessments
    - Wechsler Adult Intelligence Scales
    - Stanford-Binet Intelligence Scale
    - Woodcock-Johnson Tests of Cognitive Ability
  - Adaptive functioning assessments
    - Vineland
    - Adaptive Behavior Assessment Systems
    - Assessment of Functional Living Skills
    - Developmental Assessment for Individuals with Severe Disabilities
  - Non-verbal assessments
    - Wechsler Nonverbal Scale
    - Universal Nonverbal Intelligence Test
    - Leiter International Performance Scale
- Be aware of floor effects!
  - May not accurately portray the relative strengths and weaknesses



There are many assessments for determining intelligence and adaptive functioning. These assessments have to be administered by qualified professionals. Some of the most commonly used today are the Wechsler scales for adult intelligence, but they have also been criticized for relying heavily on verbal and motor tasks which may make them less valid for assessing the range of cognitive abilities for people with verbal and motor deficits. So if the person does not primarily use verbal communication, or speaks another language, it is important that tests are selected that do not rely on verbal communication. Similarly, a person with motor deficits will need assessments that do not rely on timed tests.

It is also important to consider the “floor” of an assessment. This is the lowest possible score on the test. Some tests are designed to have lower floors than others. Where it becomes a problem is that if a person’s “true” abilities are near or below the floor of the test, the test will not be able to provide an accurate assessment of the person’s strengths and weaknesses.



## Identify IDD-Related Support Needs



- People with IDD may have more or less facility with communication
- Communication may be a struggle because a person may be nonverbal &/or use assistive communication devices
- Complex & chronic medical comorbidities (e.g., chronic lung disease, seizures & complex feeding problems) may require reliance on technologies (e.g., tracheostomies, home oxygen & gastrostomy tubes)
- Intensive coordination of services & therapies may detract from trauma-focused and related behavioral needs
- Disability Care Coordination Organizations



### Say

We've just outlined the screening & assessment process for IDD-related support needs. However, we know that identification, diagnosis and service planning of people with IDD is quite challenging.

Delivery of primary care to people with IDD presents distinct difficulties to the providers. Even basic **communication** 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 person's specific cognitive level and home and occupational resources (therapies, assistive devices) he/she may have more or less facility with communication.

Some people 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 or mental health conditions. The person's Medicaid or other healthcare program may offer care coordination through entities called Disability Care Coordination Organizations or "DCCOs" which may be able to help coordinate services to ensure that trauma-related needs don't fall through the cracks.

## Identify Trauma-Related Support Needs



- Not everyone needs trauma-focused treatment.
- Trauma screening and assessment help identify the people who most need trauma-focused therapy.
- Consider the type of trauma experienced when making service referrals & service plans.
- Assess the functioning of the caregiving system, including the impact of caregiver trauma.



### **Say**

- 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 people with IDD and their caregivers. Again, the first step is screening and assessment.
- There are different paths that may lead to trauma-informed treatment. Sometimes the trauma that a person experienced is known. Other times, a person 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 people with IDD (as we discussed in Module 1), a brief trauma screen is recommended when people with IDD and caregivers present with problems.
- Providers should consistently use a screening tool to identify a person'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.

## Identify Trauma-Related Support Needs



- Involve the person with IDD to the extent possible.
  - May need to make use of an intermediary (e.g., sign language interpreter, professional familiar with assistive devices)
- Providers should pay attention to
  - Pace (e.g., slow down speech)
  - Complexity (e.g., use simple language)
  - Timing (e.g., present one concept at a time)
  - Sequencing (e.g., rearrange questions to build on strengths)
- Involve a wide range of caregivers in the assessment process (e.g., parents, siblings, paid support staff, day program staff)



### Say

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

## Identify Trauma-Related Support Needs Screening



- Does not necessarily have to be administered by a mental health professional
- Usually includes questions regarding exposure to trauma & related symptoms
- Assists providers in understanding the person's & family's history & potential trauma reminders
- Directs trauma-informed case planning; positive screen may result in referral for comprehensive trauma mental health assessment



### **Say**

- **Trauma Screening** often may be administered by a front-line worker (e.g., service coordinator, case worker) to determine a person's trauma history and related symptoms.
- Screening for abuse and traumatic stress may include an interview with the person, the primary caregiver, or another trusted person. A person-centered approach allows identification of cultural, socioeconomic, and religious factors defining the person's values and problem-solving strategies.
- Standardized trauma screening tools may need to be adapted for people with IDD. For example, communication limitations of the person may hinder use of standardized instruments and require adaptations.
- *Ask participants how trauma screening may need to be adapted for people with IDD.*
- The purpose of screening is to identify those who need further assessment. A positive screen may result in referral for more complete assessment and treatment.
- Visit the International Society for Traumatic Stress Studies for a listing of screening and assessment tools for children and adults. While these assessments aren't specific to people with IDD, they may be able to be adapted for some people with IDD:  
<https://istss.org/clinical-resources/assessing-trauma>

## Identify Trauma-Related Support Needs



Examples of trauma screening tools for adults with IDD include

**Bangor Life Events Schedule for Intellectual Disabilities (BLESID)**

- Self-report and caregiver-report versions available at <http://www.leeuw.com/blesid/>
- Hulbert-Williams, L., Hastings, R. P., Crowe, R., & Pemberton, J. (2011). Self-Reported Life Events, Social Support and Psychological Problems in Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 24(5), 427–436. <https://doi.org/10.1111/j.1468-3148.2011.00624.x>

**Lancaster and Northgate Trauma Scales (LANTS)**

- Self-report and caregiver-report versions
- Wigham, S., Hatton, C., & Taylor, J. L. (2011). The Lancaster and Northgate Trauma Scales (LANTS): The development and psychometric properties of a measure of trauma for people with mild to moderate intellectual disabilities. *Research in Developmental Disabilities*, 32(6), 2651–2659. <https://doi.org/10.1016/j.ridd.2011.06.008>



Screening tools for trauma and traumatic stress in people with IDD have been developed, although they are not widely used in the United States by mental health or IDD providers. It is our hope that this training will encourage you and other service providers to consider adopting these or similar screening tools in your work.

The Bangor Life Events Schedule for Intellectual Disabilities (BLESID) is a checked list of traumatic or stressful life events with self-report and caregiver report versions. It includes events that are more relevant to people with IDD than traditional life event checklists. It is freely available for clinical use and has been used in a number of research studies.

The Lancaster and Northgate Trauma Scales (LANTS) is a screening tool for emotional and behavioral symptoms associated with trauma or stress. It also has self-report and caregiver versions and is available by request from the first author, Dr. Wigham.

## Identify Trauma-Related Support Needs



Examples of trauma screening tools for adults with IDD include

### Impact of Events Scale – Intellectual Disabilities

#### ▪ Self-report version

- Hall, J. C., Jobson, L., & Langdon, P. E. (2014). Measuring symptoms of post-traumatic stress disorder in people with intellectual disabilities: The development and psychometric properties of the Impact of Event Scale-Intellectual Disabilities (IES-IDs). *The British Journal of Clinical Psychology*, 53(3), 315–332.  
<https://doi.org/10.1111/bjc.12048>



The Impact of Events Scale – Intellectual Disabilities is an adaptation of a the Impact of Events Scale – Revised, originally developed for adults with typical development. The IES-ID is a self-report screening tools for adults with ID and has promising psychometric properties.

## Identify Trauma-Related Support Needs



- Many caregivers have histories of trauma (in childhood & adulthood).
- Trauma can impact caregiving & protective capacities.
- Awareness of caregiver trauma history helps providers better understand caregivers and link them to appropriate services.
- Examples of screening tools for caregivers:
  - Parent Emotional Reaction Questionnaire
  - Life Events Checklist
  - Trauma Recovery Scale



### Say

- Caregivers of people 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 the people they support
- When screening caregivers for traumatic experiences, it may also be appropriate to ask about other members of the family (e.g., parents/siblings).
- Examples of screening tools for caregivers:

- **Parent Emotional Reaction Questionnaire:** assesses stressful parental emotional reactions to the sexual abuse of their children

- **Life Events**

- Checklist:** <http://www.ptsd.va.gov/PTSD/professional/pages/assessments/assessment-pdf/life-event-checklist-lec.pdf>

- **Trauma Recovery**

- Scale:** <http://www.psychink.com/rfiles/CFScalesMeasures.pdf>

## Identify Trauma-Related Support Needs



### Trauma Assessment

- A more in-depth exploration of the nature & severity of the traumatic events, the impact of those events, current trauma-related symptoms & functional impairment
- Includes a clinical interview, use of objective measures, behavioral observations of the person, and collateral contacts with family, caseworkers, etc
- Usually conducted by a mental health provider to drive treatment planning
- May occur over at least 2-3 sessions
- Should be used to determine the treatment plan



### Say

- **Trauma Assessment** is used if a person has a history of trauma and is currently displaying trauma symptoms. The assessment identifies the person's and caregiver's emotional and behavioral reactions to the trauma. Assessment results drive treatment planning and help determine whether the person 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 caregivers in the assessment process. This is a good time to let caregivers know what the process is (i.e., how assessment helps drive treatment planning) and how and at what point caregivers should be involved.
- The mental health provider then uses the assessment results to determine the best course of treatment, based on the person's identified needs.



## Identify Trauma-Related Support Needs



- Domains covered include:
  - Basic demographics
  - Family history
  - Trauma history (comprehensive, including events experienced or witnessed)
  - Developmental history
  - Overview of person's problems/symptoms



### Say

- Trauma assessment is comprehensive and covers multiple domains.
  - Basic demographics
  - Family history
  - Trauma history (comprehensive, including events experienced or witnessed)
  - Developmental history
  - Overview of person's problems/symptoms
- Assessment may use standardized clinical measures to assist in identifying the types and severity of symptoms the person is experiencing, as well as identify their unique risk and protective factors.
- An effective assessment will engage caregivers and incorporate their input.
- Assessment provides a structured framework to identify the clinical needs of the person.
- Assessment helps to clarify what kind of treatment is most appropriate for the person (e.g., trauma-informed treatment or other kinds of treatment).
- Assessments may need to be adapted for people with IDD. *[Ask participants how trauma assessments may need to be adapted for people with IDD.]* We will discuss this more in a few moments.

## Identify Trauma-Related Support Needs



## Classification Systems



### **Say**

In module 3, we briefly discussed the symptoms of posttraumatic stress and some of the trauma and stress-related disorders. If you are a mental health professional responsible for assessing and diagnosing mental health disorders, you are likely familiar with either the Diagnostic and Statistical Manual of Mental Disorders 5, or DSM-5, or the International Classification of Disease – 10, or ICD-10. These are the 2 primary classification systems used to identify and diagnose trauma-related mental health disorders.

- The DSM-5 is used primarily in psychological and psychiatric settings for diagnosing mental health disorders.
- The ICD-10 is used primarily in medical settings and includes both physical health and mental health disorders. The mental health categories overlap significantly with the DSM-5.

You may not be familiar with the Diagnostic Manual – Intellectual Disabilities 2. The DM-ID 2, is an adaptation of the DSM-5 that was developed for diagnosing mental health disorders in people with IDD. It provides recommended modifications to the standard DSM criteria based on level of ID and it is highly recommended for mental health practitioners who work with people with ID.



## Adaptations to Diagnostic Criteria for PTSD

As recommended by DM-ID 2

- **A. Trauma Exposure:** Lower developmental age associated with lower threshold of what might be considered traumatic
- **B1. Distressing Memories:** Behavioral acting out and self-injury may be symptomatic for those with greater cognitive impairment
- **B2. Recurrent Dreams:** Distressing dreams without recognizable content may be more common in people with more severe cognitive impairment
- **B3. Dissociative Reactions:** Trauma-specific reenactments may be confused with symptoms of psychosis in adults with IDD
- **B4. Distress to Internal or External Cues:** May appear as disorganized or agitated behavior in people with greater cognitive impairments

Here we provide some examples for how the DM-ID 2 adapts the diagnostic criteria for people with ID.

- For Criterion A - Trauma Exposure, the DM-ID 2 recommends considering a lower threshold for what might be considered traumatic the lower the person's developmental level. In other words, what might be considered a "stressful" experience for a person with typical development may be considered traumatic for a person with ID.
- For Criterion B1 – Distressing Memories – providers should consider whether behavioral acting out or self-injury may be a symptom of distressing memories.
- For Criterion B2 – Recurrent Dreams – the DM-ID emphasizes that trauma-related dreams may not have recognizable content, particularly for those with more severe cognitive impairment.
- For Criterion B3 – Dissociative Reactions – It is important to be aware that trauma specific reenactments may be confused with symptoms of psychosis in adults with IDD.
- For Criterion B4 – Distress related to internal or external trauma reminders may appear as disorganized or agitated behavior.



## Adaptations to Diagnostic Criteria for PTSD

As recommended by DM-ID :

- **C. Avoidance of Trauma Cues:** Like trauma exposure threshold, the threshold for what may activate a trauma reaction may lower and broaden and result in a lowering and broadening of the avoidance
  - May be reported as "noncompliance" for individuals unable to verbalize reasons for avoidance
- **D1. Inability to Recall Details of Traumatic Event:** May be associated with cognitive impairment and requires careful assessment

- For Criterion C - Avoidance of Trauma Cues the threshold for what may activate a trauma reaction may lower and broaden and may be reported as "noncompliance" for individuals unable to verbalize reasons for avoidance
- For Criterion D1 - the Inability to Recall Details of Traumatic Event: May be associated with cognitive impairment and requires careful assessment

## Identify Trauma-Related Support Needs



### DM-ID-2 Workbook

- Structured diagnostic method for mental health professionals.
- Incorporates structured caregiver interview for observable signs
- Guides clinicians in making more accurate diagnoses.



### Say

The DM-ID 2 has developed a structured diagnostic approach to making accurate mental health diagnoses of people with IDD. It relies upon observable signs of mental illness and includes a mental health interview for caregivers.

The structured approach and decision trees in the workbook help to identify and properly classify symptoms that might be easily overlooked or overshadowed.

## Identify Trauma-Related Support Needs



### IDD- & Trauma-Informed Services & Treatment

- Trauma-Informed Services: refers to a broad array of support & care, including treatment
  - Advocacy
  - Case Coordination
- Trauma-Informed Treatment: refers to interventions that focus on addressing symptoms & responses to traumatic experiences
  - Continuous Assessment
  - Cross-System Partnerships



### Say

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

**Trauma-informed services** refers to a broad array of support and care, including treatment, that incorporates an understanding of the effects of trauma and aims to use practices that promote healing and resist re-traumatization. It may necessitate service providers to engage in advocacy on behalf of the person with IDD to insure that trauma is considered and addressed and increased case coordination to ensure that appropriate services are provided.

**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.

## Identify Trauma-Related Support Needs



### Developing IDD- & Trauma-Informed Recovery Plans

- Identify what is important to the person.
  - Recognize the person's talents and strengths as well as needs.
  - Include the person's personal circle of significant relationships when developing a plan.
  - Identify the person's hopes and dreams, as well as fears and nightmares.
- Identify additional information that you need to gather.
  - Trauma assessment/screening
  - Protective factors to enhance
- Focus on concrete action to move toward the desired life.
  - Referrals to trauma-focused treatment
  - Referrals to other supportive services (e.g., respite, activities, parent trauma)



### **Say**

- 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 person 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 person.

# PUTTING IT INTO PRACTICE: FISH BOWL

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In this activity, we will be using a role play to consider the perspective of people with IDD and/or their caregivers and providers when accessing services.

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 person with IDD and/or their 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 person with IDD your caseload to role play.

Once the activity starts the provider will begin asking the person with IDD and/or their family member questions to start the process of getting them closer to an 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, person with IDD and/or their 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 change next time you are confronted with the same situation, etc..





Let's talk now about what might go into those recovery plans, particularly for clients who are experiencing significant symptoms of trauma-related symptoms who need supports and interventions that are trauma-informed or trauma-specific.

## Trauma-Informed Evidence-Based Treatments

There are many different evidence-based trauma-informed treatments. A trauma-informed mental health professional should be able to determine which treatment is most appropriate for a particular person and/or their caregivers.

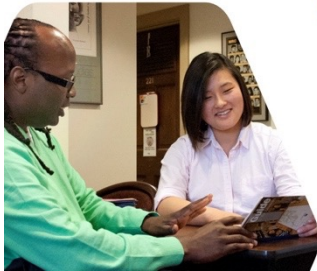
- Cognitive Processing Therapy
- Cognitive Therapy
- Individual CBT with a Trauma Focus
- Prolonged Exposure
- Eye Movement Desensitization and Reprocessing (EMDR)
- For fact sheets on treatments:
  - <http://www.istss.org/treating-trauma/new-istss-guidelines.aspx>



### **Say**

- This slide lists some examples of evidence-based treatments that are used with people who have experienced trauma.
- The website of the International Society for Traumatic Stress Studies (ISTSS) (<http://www.istss.org/treating-trauma/new-istss-guidelines.aspx>) 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 experiences. Are they using them with people with IDD?]*
- It is helpful for participants to hear about if these treatments are being used with people with IDD and to know which community providers are trained to provide trauma treatment.

## How do trauma treatments work?

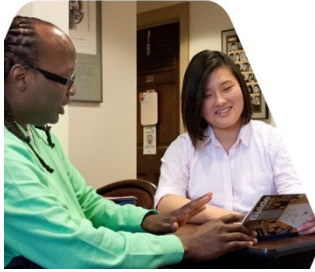


- Many effective trauma treatments rely on cognitive behavioral strategies:
  - Teach stress management & relaxation skills to cope with unpleasant feelings about the trauma
  - Utilize “exposure strategies” (i.e., talking about the traumatic experience at a speed that controls the level of distress for the person)
  - Create a trauma “narrative” or story of what happened in order to master painful feelings about the experience & resolve the impact of the experience
  - Explore potentially untrue ideas about what happened & why
  - Change unhealthy/incorrect views
  - May involve parents or other caregivers

### Say

- There is no “one size fits all” when it comes to treatments for people 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 person’s trauma history and needs.
  - After the assessment, the provider proposes a treatment plan, which includes involvement of parents, family, or guardians in the person’s therapy.
- Trauma-informed therapy actively addresses the person’s traumatic experiences and traumatic stress symptoms. This type of treatment has been proven effective for people of every age, from infants and toddlers to teenagers, to adults. It is never “too late” for a person to seek treatment for trauma-related responses.
- Sometimes there may be a lack of caregivers who can provide an accurate history of trauma experienced by the person (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 person’s perception of what happened, and/or their ability to communicate about it.
- Many effective trauma treatments rely on cognitive behavioral strategies to help people challenge thoughts that are not serving their recovery.
- These strategies allow people 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:

## How do trauma treatments work?



- Many effective trauma treatments rely on cognitive behavioral strategies:
  - Teach stress management & relaxation skills to cope with unpleasant feelings about the trauma
  - Utilize “exposure strategies” (i.e., talking about the traumatic experience at a speed that controls the level of distress for the person)
  - Create a trauma “narrative” or story of what happened in order to master painful feelings about the experience & resolve the impact of the experience
  - Explore potentially untrue ideas about what happened & why
  - Change unhealthy/incorrect views
  - May involve parents or other caregivers

Cont.

- Teaching people **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 person.
- Creating a coherent “**narrative**” or story of what happened. It is often a difficult process for people 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 untrue or distorted ideas** about what happened and why. People 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 person stop prolonging the traumatic stress by punishing him- or herself.
- **Changing unhealthy and incorrect views** that have resulted from the trauma. People often need help to overcome such ideas as “if he did that bad thing to me it must be because I’m bad” or “people like me can never have a normal life again.”
- **Involving caregivers.** Caregivers can play an important role in treatment, sometimes by participating in interventions with the therapist and by helping the person practice new therapeutic strategies at home. Caregivers have key information about their person that therapists need in developing and implementing treatment. Most importantly, caregivers can create the stable, consistent and caring environment in which the person 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 people with IDD. On the next slide, we’ll review some adaptations for people with IDD.

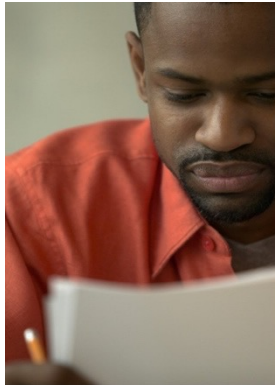
## Adaptations to Trauma-Focused Treatment

- Increased psychoeducation
  - Building an emotion vocabulary
  - Differentiating between thoughts, feelings, and behaviors
- Modify pace
- Frequent review of concepts
  - Practice skills multiple times in session
- Generalization Training
  - Increased opportunities to practice out of session
  - Practice in as many settings as possible
  - Enlist caregivers and support



VCU WITH

One of the core challenges for many people with IDD is difficulty transferring learning from one setting to another. They may learn and demonstrate a skill at a day program, but have difficulty demonstrating that same skill in the workplace. Similarly, they may practice and learn calming skills in therapy, but have difficulty doing so at home, work, or day program. Therapists will need to work with their client and his or her support network to identify the settings that are likely to be challenging and create opportunities to practice the new skills in these settings.



### Trauma-Focused CBT Adaptations for People with IDD

- Be creative in the ways in which the narrative is recorded
  - Dictate responses
  - Use a tape recorder, video or still camera
  - Role-play, sing or dance
  - Use play
- Slow down pace
  - Allow additional time to share thoughts & feelings about traumatic experience
- Recognize that repetition is helpful for learning
  - A person with IDD may return repeatedly to inaccurate or unhelpful cognitions

Source: Brian Tallant, LPC, Aurora Mental Health Center



### Say

- 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-soothe
  - Feelings of competency to deal with challenging situations

- Ideas for adapting psychotherapy for people 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.

#### Trauma Services & Treatment Adaptations for People with IDD

- Be sure that all members of the caregiving team are using the same language to address the traumatic experience(s).
- Check for comprehension—don't assume that the material is too complex for the person to understand.
- Use multisensory interventions (e.g., non-verbal, play therapy) & tools to assist in learning.
- Allow more time for the client to learn the skills & use more repetition.
- Work explicitly on generalization of skills to other environments.



#### Say

- IDD may impact a person'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 people 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 people 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 person who has limited verbal abilities to address reminders (e.g., teach the person 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 people with IDD.]*

### Learning more about CBT strategies for People with Intellectual Disabilities

- Book: "Cognitive Behaviour Therapy for People with Intellectual Disabilities: Thinking creatively" by Andrew Jahoda, Biza Stenfert Kroese, and Carol Pert. Published by Palgrave Macmillan
- Book: "The Emotion Regulation Skills System for Cognitively Challenged Clients: A DBT-Informed Approach" by Julie Brown. Published by Guilford Press
- Online Course: "Tailoring Trauma-Focused Cognitive Behavior Therapy for Children with IDD." The National Child Traumatic Stress Network's Learning Center <https://learn.nctsn.org/enrol/index.php?id=566>
- Online Course: "Using Cognitive Behavioral Therapy with Persons with IDD." Relias Academy <https://reliacademy.com/rls/store/browse/productDetailSingleSku.jsp?&productId=c1110648>



There are several resources for clinicians who are interested in developing skills to adapt trauma-specific or other therapeutic approaches for people with IDD. A few are:

The book "Cognitive Behaviour Therapy for People with Intellectual Disabilities: Thinking creatively" by Andrew Jahoda, Biza Stenfert Kroese, and Carol Pert.

The book Book: "**The Emotion Regulation Skills System for Cognitively Challenged Clients: A DBT-Informed Approach**" by Julie Brown. Published by Guilford Press

The National Child Traumatic Stress Network's Learning Center offers a webinar titled "Tailoring Trauma-Focused Cognitive Behavior Therapy for Children with IDD." Although this treatment is focused on children, most of the concepts and strategies will generalize to therapists treating adults with IDD.

<https://learn.nctsn.org/enrol/index.php?id=566>

Relias Academy offers a course titled: Using Cognitive Behavioral Therapy with Persons with IDD. <https://reliacademy.com/rls/store/browse/productDetailSingleSku.jsp?&productId=c1110648>





### IDD- & Trauma-Informed Services & Treatment: Questions to Ask

- Do you provide services to people with IDD who have had traumatic experiences?
- How do you approach therapy with people & their caregivers who have had traumatic experiences (regardless of whether they indicate or request trauma-informed treatment)?
- Do you provide trauma-specific or trauma-informed therapy? If so, how do you determine whether the person needs trauma-informed therapy (e.g., screening/assessment tools)?
- How familiar are you with evidence-based treatment models designed & tested for treatment of person trauma-related symptoms?
- Can you describe the core components of your treatment approach?

### **Say**

- 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 people who have been impacted by trauma need and deserve a specialist, just as people with serious dental problems need an orthodontist.



### Other Services That Enhance Resilience & Recovery

- Mentoring programs
- Sports, arts, recreational activities
- Community service
- Wraparound programs



### **Say**

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

## Trauma & IDD: Create an Integrated System of Care



### For Your Eyes Only

- There is animation on this slide. Names of systems will pop up randomly.

### Say

- Due to overlapping disabilities, quality trauma treatment involves integrated care between caregivers, 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 person and family in a holistic manner. When different systems have many different and potentially competing priorities, there is a risk that people with IDD and their caregivers 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 person. For example, in some communities, when sexual abuse occurs, the person 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 people with IDD from further abuse, these interventions can be immensely stressful for people with IDD.
- People with IDD and their caregivers often have legal issues (denial of benefits, special education, person welfare/juvenile justice involvement). Attorneys and judges could use some guidance on trauma & IDD.

## Strategies for Cross-System Collaboration



- Cross-train on the intersection of trauma and IDD
- Jointly develop protocols regarding trauma and collaborative services that promote resiliency
- Create multi-disciplinary teams
- Schedule regular team meetings
- Co-locate staff in clinics & community “hubs”
- Identify & utilize cross-system assessment tools
- Share knowledge of local resources & trauma-informed treatment options
- Integrate information-sharing systems



### **For Your Eyes Only**

•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.

### **Say**

•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 person anymore.

**Activity –  
Putting It Into Practice—  
Case Vignettes:  
Accessing Services**



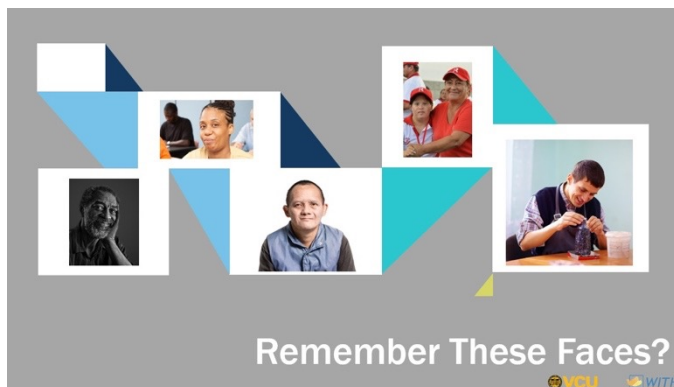
**For Your Eyes Only**

*This slide is an Activity. Participants will use two handouts for this activity, **Putting It Into Practice—Case Vignettes: Accessing Services** and **Protective Factors**.*

**Say**

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 practice identifying protective factors and determining trauma and IDD informed supports and service needs.

*Advance to the next slide for details.*



*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 person they have been assigned, anticipate challenges & barriers they may encounter with that person, and in what ways—keeping screening and assessment in mind—that they can advocate for the person. 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.*

### **Say**

- Working with your group 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 caregivers 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 person for additional services and/or treatment?
  - We'd like you to identify what the challenges and barriers for the person in your assigned case. How might that person have difficulties accessing services, etc..
  - And finally, we'd like you to come up with a few ways that you would advocate for this person. What would you want to screen for? Start thinking about what planning for services would look like with this person. *[Allow 20 minutes for this discussion. Have a participant at each table briefly report out on what they would do.]*

# PUTTING IT INTO PRACTICE: CASE VIGNETTES: ACCESSING SERVICES

---

Read the case vignette your group has been assigned and answer the following questions. You may want to refer to the Protective Factors handout to give you some ideas.

- Are there protective factors that you want to keep in mind when identifying screening/assessment and/or treatment for this person and their caregivers? Are there protective factors that can be built upon in treatment? If you are unaware of any protective factors how would you cultivate some with this person and/or their caregivers?
  
- What challenges/barriers/risk factors do you anticipate coming up for this person and their caregivers? Do you think the challenges/risk factors will impact their ability to access services?
  
- What are three things you could do to advocate for this person and/or their caregivers to help them overcome these challenges?

# PROTECTIVE FACTORS CHECKLIST

---

- ☐ Ask & answer questions of the person with IDD and their caregivers
- ☐ Provide timely information
- ☐ Address traumatic experiences of the person with IDD and their caregivers
- ☐ Promote secure attachment
- ☐ Promote a healing & protective environment
- ☐ Help access IDD- & trauma-informed support and services
- ☐ Partner with the person and caregivers to create a recovery team
- ☐ Help navigate systems of care, including systems challenges
- ☐ Offer community resources
- ☐ Connect people and families with supportive peers and mentors
- ☐ Refer for formal support if needed
- ☐ Encourage connection with any spiritual communities
- ☐ Connect the person and caregivers with cultural community
- ☐ Build & encourage family cohesion
- ☐ Promote supportive interactions between the person with IDD and their caregivers
- ☐ Build social skills
- ☐ Address cognitive functioning
- ☐ Promote self-efficacy skills



### Essential Messages

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



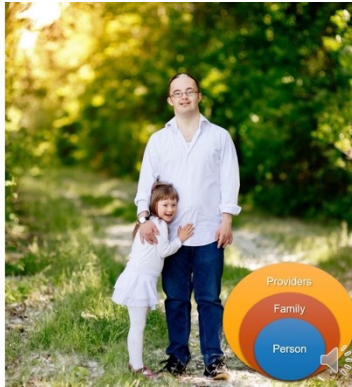
### Say

•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 person-centered services, treatments and systems drive the recovery plan.

## What Can a Provider Do?

- Identify the developmental level of the person in order to guide appropriate selection of trauma screening/assessment tools, services & treatments.
- Facilitate the person's self-determination
- Coordinate continuous care through communication with therapists and other providers on a regular basis.
- Participate in cross-training with other agencies and systems on issues related to trauma and trauma-informed care.
- Identify and interview local individuals/agencies



## For Your Eyes Only

• *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.*

## Say

• Here are some things that you as a provider can do to address the concepts that we discussed in Module 5. Think about the person you identified at the end of Module 1 who connects you to this work. What can help that person and other people 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.]*

## Activity – Action Planning

Essential Messages 8 & 9



### For Your Eyes Only

*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.*

*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.*

### Say

Pull out your handout titled, **Action Planning: Essential Message 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 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 activity is done ask 2-3 people to share one strategy they think they would like to implement starting tomorrow.]*

# ACTION PLANNING

## ESSENTIAL MESSAGES 8 & 9

---

Think about the person you identified at the end of Module 1 that connects you to this work. What can help that person and other adults with IDD who have experienced trauma? (Put an “X” in up to 3 boxes next to the ideas you think you would MOST like to emphasize in your daily practice.)

### 8

#### ESSENTIAL MESSAGE 8

Partner with agencies and systems to ensure earlier and more sustained access to services.

- ☐ Over the next 3 months, I will identify 3 local agencies that provide **advocacy** for adults with IDD. I will attempt to make contact with at least 1 person in each agency.
- ☐ Over the next 3 months, I will identify 3 local organizations that provide **intensive case management or care coordination services** for adults with IDD. I will attempt to make contact with at least 1 person in each organization.
- ☐ Over the next 3 months, I will identify 3 local clinics/providers that provide **trauma-informed assessments** for adults. I will attempt to make contact with at least 1 person in each clinic.
- ☐ Over the next 3 months, I will identify 3 local clinics/providers that provide **trauma-informed treatment** for adults. I will attempt to make contact with at least 1 person in each clinic.
- ☐ (**Write my own.**) Over the next 3 months, I will...

# ACTION PLANNING

## ESSENTIAL MESSAGES 8 & 9

---

### 9

#### ESSENTIAL MESSAGE 9

Ensure that trauma-informed person-centered services, treatments, and systems drive the recovery plan.

- ☐ Over the next 3 months, I will review the standardization, reliability, and validity information for 1 of the trauma screening or assessment tools I use to determine the appropriateness of use for adults with IDD.
- ☐ Over the next 3 months, I will identify a trauma screening tool and use it with 3 adults with IDD who have experienced trauma.
- ☐ Over the next 3 months, I will identify a tool to assess parent/caregiver trauma and use it with 3 caregivers of adults with IDD who have experienced trauma.
- ☐ Over the next 3 months, I will identify 3 adaptations I can make to my treatment of choice for 3 adults with IDD who have experienced trauma.
- ☐ (Write my own.) Over the next 3 months, I will...

# Module Six

Provider Self-Care



### **Say**

•In Module five, we looked at how to enhance protective factors of people with IDD and caregivers through IDD-informed trauma assessment, screening, and referral to appropriate trauma-informed services and treatment. •Module six discusses caregiver and provider needs and the steps to reduce stress and increase self-care for providers.

## Module Five: Learning objectives

What Will I Learn Today?

- |    |  |
|----|--|
|    | Describe the difference between secondary traumatic stress, burnout and vicarious trauma.                      |
| 1. |  |
| 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.   |



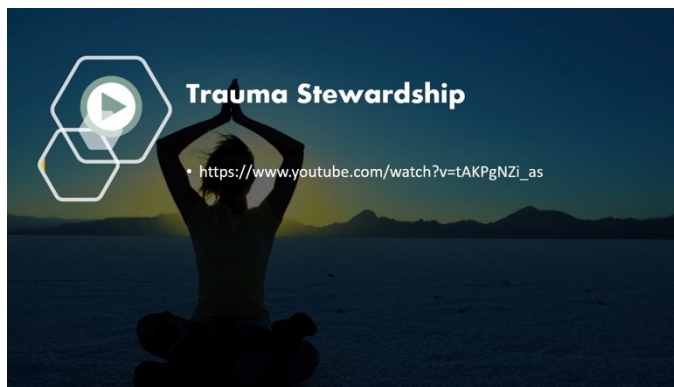
### Facilitator Note:

#### Say

•After completing module six, you should be able to:

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.





### **For Your Eyes Only**

- **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.*
- 

### **Say**

- Source: Developed by traumastewardship.com. Video can be streamed from: [https://www.youtube.com/watch?v=tAKPgNZi\\_as](https://www.youtube.com/watch?v=tAKPgNZi_as)

- **Secondary Traumatic Stress** (STS) refers to the development of post-traumatic stress symptoms caused by at least one indirect exposure to traumatic material.
- **Burnout** refers to emotional exhaustion, depersonalization, and a reduced feeling of personal accomplishment. Burnout develops as a result of general occupational stress.
- **Vicarious trauma** refers to changes in the inner experience of the therapist, resulting from empathetic engagement with a traumatized client. It focuses less on trauma symptoms and more on the changes that occur following cumulative exposure to another person's traumatic experience(s).



### **Say**

- There are multiple ways that people talk about Secondary Traumatic Stress. Let us talk about three types.
- (Click the remote or press the space bar). There are slight variations in the descriptions that should be understood before diving into a personal self-care plan and a plan to tackle stress in your organization.



## Provider Burnout

- Caseload that requires intensive case coordination
  - Need for Advocacy
  - Need for Collateral Engagement
- Longer therapeutic process & treatment times
- Working in a stressed system
- Identifying ways to adapt screening, assessment & interventions takes time



### Say

- The complexity of needs of people with IDD who have experienced trauma can result in high-intensity jobs including:
  - Needs of people with IDD
  - Needs of caregivers
  - Multi-agency involvement
  - Administrative demands (paperwork, office management)
  - High caseloads
- Programming for people with IDD often includes detailed 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 highly trained behavioral clinicians; providers can experience high stress levels, burnout and feel ill-equipped to manage all the aspects of care.
- People with IDD and trauma exposure may have challenging behavior. Behavioral problems create significant challenges in *providing safety and support* to providers as people with IDD may require high levels of supervision, and staff injuries and high staff turnover can occur.
- Identifying adaptations to support people with IDD may feel rewarding at times and frustrating at other times. •Provider burnout, *emotional instability*, and *high turnover* may reduce IDD and staff members' physical and emotional safety.



### **For Your Eyes Only**

- There are several animations on this slide. You will have to initiate the animations for the slide content. Please be aware of when you will need to click the remote or press the space bar.

### **Say**

•Because of the work we do as helping professionals, it is easy to overlook symptoms of secondary traumatic stress. The following warning signs indicate you could be experiencing STS.

- (Click the remote or press the space bar). **Chronic exhaustion**—you feel as if you do not have the time or energy to do all that needs to be done. You may wonder whether what you are doing constitutes worthwhile work.
- (Click the remote or press the space bar). **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.
- (Click the remote or press the space bar). **Social withdrawal**—you turn down social engagements, withdraw from intimacy with your spouse, and overlook commitments you have made with your people.
- (Click the remote or press the space bar). **Avoidance**—the phone rings or your pager goes off, and you think, "I am 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 cannot go in that day.
- (Click the remote or press the space bar). **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 leave later. You make executive decisions that may intrude on the work areas or job functions because you believe that is more efficient than asking someone's opinion.
- (Click the remote or press the space bar). **Anger/Cynicism**—you begin to think there is no hope. You are suspicious of everyone's motives.
- (Click the remote or press the space bar). **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.
- (Click the remote or press the space bar). **Illness**—you may begin to experience pain or illnesses. Your body is telling you that it is overwhelmed.
- (Click the remote or press the space bar). **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 experience symptoms similar to those who have had traumatic experiences.

## Activity – Stress Warning Signs



This is an activity slide. Ask participants to complete the handout "Stress Warning Signs."

### **Say**

Now let us take a look at our warning signs. Please complete your worksheet entitled *Stress Warning Signs*.

- 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]*

# STRESS WARNING SIGNS

---

Fill in the blanks below using the text in parentheses as your guide to learn more about your own stress warning signs.

- I know that my stress level is beginning to affect my relationships when

I \_\_\_\_\_, \_\_\_\_\_,  
(Identify a behavior or action verb) (Identify a behavior or action verb)

and \_\_\_\_\_.  
(Identify a behavior or action verb)

- Other people in my life can tell that I am stressed out when I look

\_\_\_\_\_ or \_\_\_\_\_, or when I  
(Name an adjective that describes how you appear) (Name an adjective that describes how you appear)

sound like \_\_\_\_\_.  
(Name an unpleasant sound or noun)

- When I am feeling overwhelmed, staying connected is \_\_\_\_\_.  
(Write an adjective that says how you feel)

- The relationships in my life often \_\_\_\_\_ when my stress level is  
(Identify a verb)

elevated.



So what can we do to prevent or respond to signs of burnout, secondary traumatic stress, or vicarious trauma?

In the following slides, we'll discuss strategies to prevent and respond to these forms of stress at the individual level and then at the organizational level.

Self-care is the ability to engage in helping others without sacrificing other important parts of one's life.



An essential strategy to prevent stress is engaging in regular self-care. For many in the helping profession, we are strongly motivated to help others, and we often put the needs of others ahead of our own. We may know how important self-care is but emotionally feel guilty about taking time for ourselves or feel overwhelmed that we feel there is no time for self-care. Let us take a deeper look at what self-care is and what it is not...

- 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.



## Activity – Self Care Options



*This is an Activity Slide: Participants will read through the **Self Care Options** handout and pick one strategy from each category.*

Self-care does not have to be time-consuming. As lovely as it would be to take an extended vacation, most of us do not have the time for that.

*[Pass out the Self-Care Options handout or direct participants to the Self-Care Options worksheet in the Participant Manual and have participants pick one from each category that they can do.]*

The Self-Care Options worksheet lists examples of behavioral strategies for self-care that you can do each day whether you have 2 minutes, 5 minutes, 10 minutes, or 30 minutes. Pick a few options that you would like to use regularly. You might even consider hanging it on the wall in your office or at home to remind you at the moment that there are things you can do to take care of yourself so that you can take care of others.

In addition to these behavioral strategies, cognitive strategies support our well-being, such as considering our beliefs about helping people with IDD. For example, belief in the effectiveness of trauma-informed interventions for the person and family you are working with can decrease STS effects. Seeing the benefit of your work is as essential as getting a break from it.

# SELF-CARE OPTIONS

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Below are some tips for using the time that you do have for self-care effectively. Carve out time each day to engage in self-care, even if you only have 2 minutes.

## If you have...

### 2 minutes

- ☐ Breathe
- ☐ Stretch
- ☐ Daydream
- ☐ Take your stress temperature
- ☐ Laugh
- ☐ Doodle
- ☐ Acknowledge one of your accomplishments
- ☐ Say no to a new responsibility
- ☐ Complement yourself
- ☐ Look out the window
- ☐ Spend time with your pet
- ☐ Share a favorite joke

### 5 minutes

- ☐ Listen to music
- ☐ Have a cleansing cry
- ☐ Chat with a co-worker
- ☐ Sing out loud
- ☐ Jot down dreams
- ☐ Step outside for fresh air
- ☐ Enjoy a snack or make a cup of coffee/tea

### 10 minutes

- ☐ Evaluate your day
- ☐ Write in a journal
- ☐ Call a friend
- ☐ Meditate
- ☐ Tidy your work area
- ☐ Assess your self-care
- ☐ Draw a picture
- ☐ Dance
- ☐ Listen to soothing sounds
- ☐ Surf the web
- ☐ Read a magazine

### 30 minutes

- ☐ Get a massage
- ☐ Exercise
- ☐ Eat lunch with a co-worker
- ☐ Take a bubble bath
- ☐ Read non-work related literature
- ☐ Spend time in nature
- ☐ Go shopping
- ☐ Practice yoga
- ☐ Watch your favorite television show

### The A-B-C's of Self-Care

- Awareness
- Balance
- Connection



VCU WITH

### **Say**

- We will now 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 aspects:
- Awareness
- Balance
- Connection—the “ABCs” of self-care.



### **For Your Eyes Only**

- There is a short activity on this slide.

#### **Say**

- The first step in self-care 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, your stress level, and what types of thoughts are going through your head.
- Self-care begins with self-awareness. Knowing your warning signs, understanding what works for you to build and maintain a sustainable self-care plan. Over the long term, this means building self-care routines and rituals into your personal and professional life.

In the short term, we can create moments of awareness simply by pausing to take a breath.

*[Optional breathing exercises:*

*If you can play media during the workshop, you may consider playing a brief meditation or breathing exercise from youtube, Calm.com, or one of many stress and relaxation-focused websites. A resource from Special Olympics Strong Minds is a great brief tool to use: [https://media.specialolympics.org/resources/health/disciplines/strongminds/mindfulness-recordings/Strong-Minds-Wellness.mp3?\\_ga=2.230806039.929001959.1627048019-2034115573.1623945109](https://media.specialolympics.org/resources/health/disciplines/strongminds/mindfulness-recordings/Strong-Minds-Wellness.mp3?_ga=2.230806039.929001959.1627048019-2034115573.1623945109) ]*

*[Alternately, you may lead the group in a simple breathing exercise..]*

- 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 breathe in and out slowly, put your hand on your abdomen, feeling it expand and contract with each breath.
- Continue to breathe 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 two minutes, noticing how your body responds.
- This exercise you can easily do at your desk between meetings or even while sitting in traffic.



### Balance



VCU WITH

### **Say**

- The second step in self-care is seeking balance among your activities. These include work, personal and family life, rest, and leisure. You will be more productive when you have had opportunities to rest and relax.
- Taking care of yourself involves far more than relaxing. It requires that you engage in (click the remote or press the space bar):
- Physical self-care
- Psychological self-care
- Emotional self-care
- Spiritual self-care
- Professional or workplace self-care

## Activity – Balancing Your Self Care



*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 will ask someone to share, but please give yours an example to generate other responses or conversations if people do not speak up.*

Please refer to your sheet entitled **Balancing Your Self-Care**. Read through the tool and identify a couple of strategies to 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.]

# BALANCING YOUR SELF-CARE

This assessment tool provides an overview of effective strategies to maintain self-care. Look through the list and see if there are one or two items you can start doing tomorrow.

## Physical Self-Care

- ☐ Eat regularly (e.g. breakfast, lunch and dinner)
- ☐ Eat healthy
- ☐ Exercise
- ☐ Get regular medical care for prevention
- ☐ Get medical care when needed
- ☐ Take time off when needed
- ☐ Get massages
- ☐ Dance, swim, walk, run, play sports, sing, or do some other physical activity that is fun
- ☐ Take time to be sexual -- with yourself, with a partner
- ☐ Get enough sleep
- ☐ Wear clothes you like
- ☐ Take vacations, day trips, or mini-vacations
- ☐ Make time away from telephones
- ☐ Other:

## Psychological Self-Care

- ☐ Make time for self-reflection
- ☐ Have your own personal psychotherapy
- ☐ Write in a journal
- ☐ Read literature that is unrelated to work
- ☐ Do something at which you are not expert or in charge
- ☐ Decrease stress in your life
- ☐ Let others know different aspects of you
- ☐ Notice your inner experience --listen to your thoughts, judgments, beliefs, and feelings
- ☐ Practice receiving from others
- ☐ Be curious
- ☐ Say "no" to extra responsibilities sometimes
- ☐ Other:

## Emotional Self-Care

- ☐ Spend time with others whose company you enjoy
- ☐ Stay in contact with important people in your life
- ☐ Give yourself affirmations, praise yourself
- ☐ Re-read favorite books, watch favorite movies
- ☐ Identify comforting activities, objects, people, relationships, places and seek them out
- ☐ Allow yourself to cry
- ☐ Find things that make you laugh
- ☐ Express your outrage in social action, letters and donations, marches, protests
- ☐ Other:

## Spiritual Self-Care

- ☐ Make time for reflection
- ☐ Spend time with nature
- ☐ Find a spiritual connection or community
- ☐ Be open to inspiration
- ☐ Cherish your optimism and hope
- ☐ Be aware of nonmaterial aspects of life
- ☐ Try at times not to be in charge or the expert
- ☐ Be open to not knowing
- ☐ Identify what is meaningful to you and notice its place in your life
- ☐ Meditate
- ☐ Pray
- ☐ Sing
- ☐ Spend time with children
- ☐ Have experiences of awe
- ☐ Contribute to causes in which you believe
- ☐ Read inspirational literature (talks, music, etc..)
- ☐ Other:

## Workplace or Professional Self-Care

- ☐ Take a break during the workday (e.g. lunch)
- ☐ Take time to chat with co-workers
- ☐ Make quiet time to complete tasks
- ☐ Identify projects or tasks that are exciting and rewarding
- ☐ Set limits with your clients and colleagues
- ☐ Balance your case load so that no one day or part of a day is "too much"
- ☐ Arrange your work space so it is comfortable and comforting
- ☐ Get regular supervision or consultation
- ☐ Negotiate for your needs (benefits, pay raise)
- ☐ Have a peer support group
- ☐ Develop a non-trauma area of professional interest
- ☐ Other:

## Balance

- ☐ Strive for balance within your work-life and workday
- ☐ Strive for balance among work, family, relationships, play and rest
- ☐ Other:



## Connection



### Say

- The third step in self-care is connection. One of the most potent stress reducers is social connection. It involves building connections and supportive relationships with your co-workers, friends, family, and community.
- 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 dinner.



## Organizational Stress

Organizations, like individuals, are living, complex, adaptive systems. They are vulnerable to stress, particularly chronic & repetitive stress.



VCU WITH

### Say

- Stress in organizations can also increase personal and secondary traumatic stress Organizations, like individuals, are living, complex, adaptive systems. They are vulnerable to stress, particularly chronic stress.

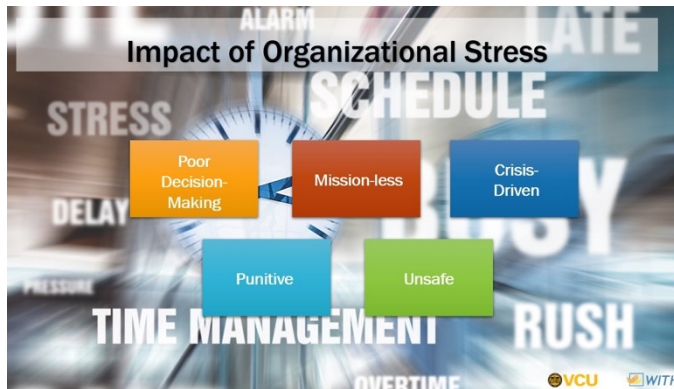
We will talk about how the organizations in which we work can lead to personal stress and how organizational stress can impact the health of the organization and the people they serve. Then we will talk about ways to improve an organizational culture that supports the people.



### **Say**

Organizational stress occurs in multiple ways. Take a moment to think about your organization.

- Examples include;
- Staff shortages
- Underpayment
- Many 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.]*



### **For Your Eyes Only**

- When the slide appears you will only see the title. There are several animations on this slide that you will have to initiate for the slide content. Please be aware of when you will need to click the remote or press the space bar.

### **Say**

• Why should Organizations care about Organizational Stress? Organizations under stress may deal with:

• (Click the remote or press the space bar) **Poor Decision-Making**—sometimes, when an organization becomes stressed, it is difficult for administrators, supervisors, and staff to make decisions, think, and focus in a way that makes sense move the organization to move forward.

• (Click the remote or press the space bar to remove the clip) **Mission-less**—under stress, an organization may lose sight of its mission. There may be multiple influences affecting its ability to carry out its original mission, and thus it appears mission-less.

• (Click the remote or press the space bar) **Crisis-driven**—the organization sees crises everywhere and attempts to focus its limited resources on a current crisis instead of a long-term plan. This can cause programs, policies, or people that were once functioning with support to become dysfunctional.

• (Click the remote or press the space bar) **Punitive**—when an organization becomes crisis-driven, it can also become punitive. Administrators set unreasonable deadlines and expect people to accomplish impossible tasks that can lead to punitive consequences when not met.

• (Click the remote or press the space bar) **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.

## Impact of Organizational Stress on Providers

- Increased absenteeism
- Impaired judgment
- Unwillingness to accept extra work
- Low motivation
- Lower productivity
- Poorer quality of work
- Greater staff friction
- Higher staff turnover



### **Say**

- Staff stress can impair organizational functioning in many ways. Here are a few:
- (Click the remote or press the space bar). 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.

### Steps to Organizational Stress Reduction

- Practice principles of safety & empowerment
- Share successes & shortcomings
- Ensure regular & reflective supervision sessions
- Support open communication
- Hold multidisciplinary case conferences



### Say

•There are several ways an organization can help workers commit to self-care, collectively and individually. You may think this does not apply to you because you are not in your organization's administrative or management position. However, you can 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 people feel safe and empowered, they are far more able to deal with challenges. Having the entire community's support, including peers and supervisors, helps everyone do their jobs better and cope with stress.

It is essential to **share both successes and shortcomings**. When successes go unnoticed, staff can start to feel like their contributions are not valued. When individuals or supervisees are blamed for shortcomings, the environment can feel punitive. Sharing successes and shortcomings create an environment of openness, learning, and mutual support.

•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 a crisis. Supervision also means listening to the supervisee, hearing what is challenging about his or her job, and when asked, offering practical assistance. Sometimes a team member needs to vent or process.

**Reflective supervision** is an approach to supervision that provides the service provider (clinical or other) with a "holding space" to process the experiences, emotions, beliefs, and values that may arise from working with traumatized populations. For an example of Reflective Supervisions consider showing the following video: <https://www.youtube.com/watch?v=opnneVjli6M>

•**Support open communication**. Most of us do not like to hear the news through the grapevine. All team members should attempt to communicate as directly and clearly as possible.

•**Hold multidisciplinary team meetings**. There is often great wisdom in collaborative planning and problem-solving. Tap into the expertise of the team and the value each team member brings to the table.

### Steps to Organizational Stress Reduction

- De-stigmatize providers' personal reactions to the work & prioritize self-care
- Provide mentoring to new professionals
- Support continuing education
- Encourage training on trauma-informed care at all levels
- Provide respite for providers



### Say

•**De-stigmatize providers' reactions to the work and prioritize self-care** are necessary for treatment planning and workplace expectations. Normalize the challenges and feelings that may result from working with clients with intensive needs and make self-care part of the organizational culture.

•**Provide mentoring to new professionals.** Remember your first days on the job? It was likely new and exciting, but there 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 also renew a seasoned staff member's energy and interest.

•**Support continuing education.** Try to support continuing education for the staff. If budgets cuts occur, it is hard to find training dollars; however, free training on the internet or in the community exists. An excellent place to start is the NCTSN Learning Center, where over 200 trauma-informed webinars with free CE credit are 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 an excellent job. Another form of respite is encouraging staff to use their vacation time. Vacation time gives staff a break from everyday exposure to traumatic situations.



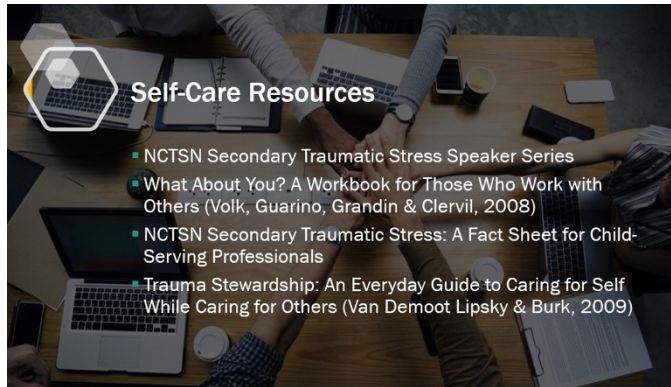
### **Say**

Another strategy for reducing organizational stress is by promoting wellness activities during the workday.

This includes providing wellness activities such as inviting visits from therapy dogs, chair massages, yoga classes, or offering mindfulness exercises during lunch breaks. Supporting staff celebrations, such as anniversaries, birthdays, and accomplishments big and small, help increase feelings of gratitude and appreciation, build personal connections, and reduce hopelessness and isolation.

Providing wellness activities in the workplace communicates to everyone the value and importance of self-care.

*[Ask the participants for examples of wellness activities from their organizations or that they think would be beneficial]*



### **Say**

We hope that if you are not already practicing regular self-care-you start

- There are many resources available to encourage and promote self-care. 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***.



## Trauma-Informed Organizational Change



The Institute on Trauma and Trauma-Informed Care (ITTIC)



<http://socialwork.buffalo.edu/social-research/institutes-centers/institute-on-trauma-and-trauma-informed-care/Trauma-Informed-Organizational-Change-Manual0.html>

If you are in a leadership role at your organization, we encourage you to consider additional steps you may take to make your organization more trauma-informed through more sustainable trauma-informed policies and practices.

As we've discussed throughout this workshop, working with your organization to establish meaningful long-term changes in policies in practices that support not only adults with IDD, but also the providers who provide care, can lead to improvements in quality of care and employee retention. Changing an organizations policies, practices, and culture can take commitment, time, and expense, but is likely to result in improved client and organizational outcomes.

The Institute on Trauma and Trauma-Informed Care (ITTIC) at the University of Buffalo has developed a manual to guide organizations in adopting trauma-informed care practices.

## Essential Messages

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



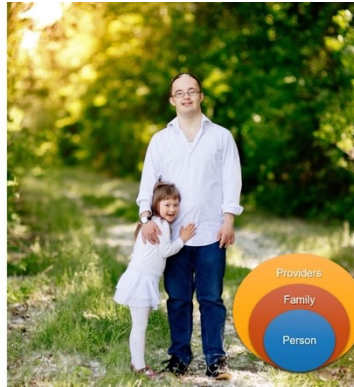
### Say

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

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

## What Can a Provider Do?

- Identify potential sources, warning signs and effects of STS and organizational stress.
- Identify strategies for stress reduction.
- Practice the ABC's of self-care.
- Identify wellness activities that could be provided in your organization.
- Identify self-care resources that you'd like to explore further.



## Say

- Here are some things that you, as a provider, can do to address the concepts that we just discussed in Module 6. *[Read the slide]*
- Think about the person you identified at the end of Module 1 who connects you to this work. What can help that person and other people 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.

## Activity – Action Planning

Essential Message 10



### **For Your Eyes Only**

•This is an activity slide that uses the handout **Action Planning: Essential Message 10** 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.

# ACTION PLANNING

## ESSENTIAL MESSAGE 10

---

Think about the person you identified at the end of Module 1 that connects you to this work. What can help that person and other adults with IDD who have experienced trauma? (Put an “X” in up to 3 boxes next to the ideas you think you would MOST like to emphasize in your daily practice.)

### 10

#### ESSENTIAL MESSAGE 10

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

- ☐ Over the next 3 months, I will designate a time to consider whether I am noticing the warning signs of stress in my relationships. I will utilize a self-care strategy when I notice that I am experiencing stress.
- ☐ Over the next 3 months, I will choose 3 tips for engaging in self-care from the Self-Care Options handout and practice 1 on a daily basis.
- ☐ Over the next 3 months, I will choose 3 strategies for maintaining self-care that I identified on the Balancing Your Self-Care handout and practice 1 on a weekly basis.
- ☐ (Write my own.) Over the next 3 months, I will...

**Activity –  
Personal Trauma-  
Informed Practice  
Action Plan**



**For Your Eyes Only**

This activity, the **Personal Trauma-Informed Practice Action Plan**, 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.

**Say**

•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. In a few months, we will contact you to ask you if you were able to implement your strategy and if not, why not.

# Personal Trauma-Informed Practice Action Plan

Go back to the strategies you identified under the Essential Messages at the end of each module. Then, select three strategies that you want to commit to implementing as part of your Personal Action Plan. Write each of these strategies in the boxes provided below, and in the corresponding box in the left hand column, write in the Essential Message number associated with each strategy.

## ESSENTIAL MESSAGES

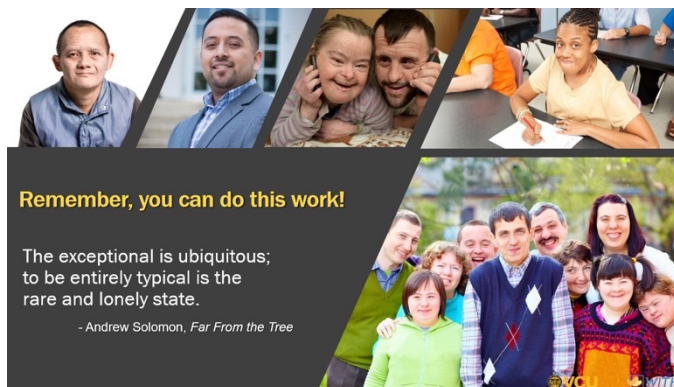
1. Know that there's hope; recovery from traumatic experiences is possible, including for adults with IDD.
2. Recognize that a person with IDD may have had a traumatic experience(s), which can have profound effects.
3. Recognize a person's developmental level and how IDD and traumatic experiences are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

# Personal Trauma-Informed Practice Action Plan

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Essential Message	Strategies I will implement over the next 3 months... (refer to the strategies you identified under Essential Messages at the end of each module)
Example:  <div>10</div>	<i>Over the next 3 months, I will set aside time to meet with each of my supervisees to assess risks for burnout or vicarious trauma and support their self-care.</i>
	Strategy 1
	Strategy 2
	Strategy 3





### **Say**

- As we said at the beginning of this training, “you can do this work!” Not only can you do it, people with IDD who have experienced trauma, and their caregivers, need you to do it.
- In his book, *Far From the Tree*, Andrew Solomon eloquently shares powerful stories that demonstrate that being exceptional is at the core of the human condition—that difference is what unites us. The crucial question is: to what extent should we accept people for who they are, and to what extent we should help them become their best selves.
- The premise of this training is that providers have the opportunity, challenge, and privilege to partner with caregivers in helping people 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 – in other words, to help them THRIVE.

## Acknowledgements

### Advisory Board

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- Michael Southam-Gerow, PhD Virginia Commonwealth University
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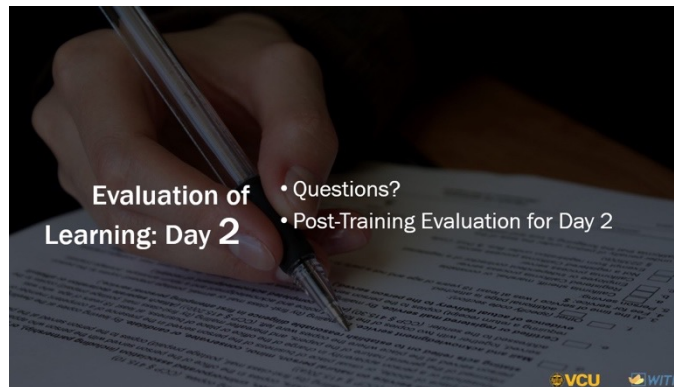
### Design

- Wadah Al Mulhim, Virginia Commonwealth University
- Shrinidhi Vijay, Virginia Commonwealth University

### Web Support

- Christian Manu, Virginia Commonwealth University
- Michael Matthews, Virginia Commonwealth University





### **For Your Eyes Only**

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

### **Say**

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

# Comprehension Check Questions - Module I

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**1. Thea has a mild intellectual disability and has experienced multiple traumas and stressful life events from the time she was a young child. She is now in her late 40s and living in a group home. Although she wants to live independently, she exhibits a number of problem behaviors including aggressive behaviors, poor self-care, and self-injury that prevent her from living by herself. Her care team suspects that these behaviors may be due in part to the traumas she experienced. What might the care team consider in her treatment plan?**

- A. Thea will probably have to live in the group home forever because her problems are too severe and have been going on for so long.
- B. A strict behavior management plan to reduce the rate of aggressive behaviors and self-injury and to increase her rate of self-care is the best way to help Thea learn to live on her own.
- C. Thea's behaviors may be influenced by trauma and she may benefit from trauma-informed therapy which has been shown to be effective for people with IDD.

**2. Which of the following statements are NOT true: Check all that apply.**

- A. Traumatic experience(s) can have profound effects on people with IDD.
- B. People with IDD experience fewer effects of trauma because they aren't as aware of what's happening to them.
- C. People with IDD experience fewer traumas because they live in protected environments.

# Comprehension Check Questions - Module 2

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**3. Which of the following statements is TRUE about development among people with IDD.**

- A. Knowing their IQ score will tell you what you need to know about their abilities.
- B. People with IDD develop at different rates across developmental domains.
- C. IDD causes a person's development to stop, so an adult with IDD is like a child.

**4. Cleo is completing an intake evaluation to determine the level of care she'll need. The interviewer wants to consider how trauma may be impacting her current level of functioning. Which should the interview consider?**

- A. Cleo's current level of functioning is affected by her current developmental level.
- B. Cleo's current level of functioning is affected by her developmental level when she experienced a trauma.
- C. Both A and B

# Comprehension Check Questions - Module 3

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**5. Which of the following are examples of traumatic stress responses that a person with IDD might experience?**

- A. Behaviorally “acting out”.
- B. Disorganized or agitated behavior.
- C. Noncompliance to requests.
- D. All of the above.

# Comprehension Check Questions - Module 4

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**6. Which of the following are examples of IDD- and trauma-informed care strategies?**

- A. Adapting trauma-focused cognitive behavioral therapy with the traumatized person using visual aids and extra practice of skills.
- B. Providing information or services to caregivers, family, and others in the person's support network to address secondary traumatic stress.
- C. Teaching caregivers to use methods such as Gentle Teaching, Positive Behavior Support, and/or Positive Identity Development to address problem behaviors and enhance adaptive communication.
- D. All of the above.

**7. Parker was trapped in his apartment for 5 days without electricity following a category 5 hurricane that devastated his city. He is exhibiting signs of traumatic stress (e.g., talking frequently about the hurricane, asking multiple times about the weather forecast for fear of another hurricane, frequent nightmares, withdrawal from social activities, etc.). Which might be part of a trauma-informed service plan for Parker? Check all that apply.**

- A. Help Parker create an emergency plan and kit with supplies.
- B. Help Parker reconnect with his friends from his day program who were displaced due to the hurricane.
- C. Help Parker's support staff access disaster relief services for themselves.
- D. Identify a therapist who has experience adapting trauma-focused CBT for people with IDD.

# Comprehension Check Questions - Module 5

---

**8. True or False: Mental health agencies are primarily responsible for managing traumatic stress in people with IDD.**

**9. Which of the following are examples of trauma-informed, person-centered behavior plans that may facilitate recovery for Min-Jun, a person with IDD who has experienced trauma? Check all that apply.**

- A. If Min-Jun engages in property destruction, he should be physically restrained for 5 minutes to prevent further damage to property or until calm. He should be redirected to complete the activity or request.
- B. Min-Jun may become agitated around female staff who resemble his mother, who abused him. If he exhibits signs of agitation (i.e., pressured speech, rapid movements, verbal aggression), staff should reassure him that he is safe and that he is loved. They should redirect him to a calming activity (i.e., go for a walk, listen to music, eating a favorite snack).
- C. Staff should support Min-Jun in developing friendships with his housemates. Min-Jun enjoys sports events and movies and staff should help Min-Jun make arrangements to attend these activities with friends frequently.



# Comprehension Check Questions - Module 6

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**10. Kamon is a case manager of a crisis support home for adults with IDD. Many of the people he supports have extensive trauma history. He has noticed that he has become increasingly pessimistic and is more likely to snap at his co-workers and has less-patience for the people he supports. He recently finished writing up the intake evaluation for someone with a particularly bad trauma history and thoughts and images of what happened to this person are keeping him up at night. Which of the following is NOT an effective form of self-care?**

- A. Taking a day off of work to work in his garden, something that he enjoys but gets little time to do.
- B. Having an extra drink of alcohol before going to bed to help him fall asleep.
- C. Talking with a supervisor about offering stress management workshops at work.
- D. Meeting a friend at a coffee shop to talk about something non-trauma related.

# Comprehension Check Questions - Key

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If you are offering a certificate of completion or continuing education credits, you may consider requiring passing a comprehension check. For the original Thriving workshops, we required a passing score of 80% or higher on the following questions and answers. You may also choose to review them with the group as an opportunity to check the comprehension of informally. These comprehension check questions are based on the Essential Messages and each one is meant to provide an example of that message in practice.

1. ANSWER: C. Research has shown that people with IDD can benefit from trauma-informed cognitive-behavioral treatments, especially those within the mild to moderate ranges of intellectual disability. Although behavior management strategies can be effective in reducing unwanted behaviors or increasing desired behaviors, they may not necessarily address the underlying biopsychosocial causes of the behaviors. This reflects Essential Message 1: Know that there's hope; recovery from traumatic experiences is possible, including for adults with IDD.

2. ANSWER: B and C. Research shows that people with IDD are at higher risk for a range of traumas and are more likely to experience PTSD and other stress-related disorders than people without IDD. Traumatic experience(s) can have profound effects on people with IDD. This reflects Essential Message 2: Recognize that a person with IDD may have had a traumatic experience(s), which can have profound effects.

3. ANSWER: B is the correct answer. People with IDD develop at different rates across many developmental domains. For example, someone might have typically developed verbal abilities but have a deficit in abstract reasoning. A is incorrect because an IQ score provides information on a very limited range of developmental domains. C is incorrect because development continues across the lifespan, even for adults with IDD. Even if their "mental age" is comparable to a child, they exhibit abilities and roles more consistent with their chronological age (e.g., occupational and social relationships). This reflects Essential Message 3: Recognize a person's developmental level and how IDD and traumatic experiences are affecting his/her functioning.

4.ANSWER: C.A person's current developmental level and their developmental level at the time of the traumatic experiences can affect his/her functioning.This reflects Essential Message 4: Utilize a developmental lens when making meaning of a person's traumatic experiences & responses.

5.ANSWER: D.All of the above.All of these could be symptoms of PTSD,although by themselves are not enough to diagnose PTSD.The presence of these symptoms warrant a thorough assessment of trauma history and trauma-related symptoms.This reflects Essential Message 5: Recognize that in the aftermath of trauma, understanding traumatic stress responses is the first step in helping someone regain their sense of safety, value and quality of life.

6.ANSWER: D.All of the above.There are many strategies for adapting evidence-based practices for adults with IDD. Small studies and case reports suggest that these can be effective in reducing symptoms of traumatic stress and improving functioning in adults with IDD who have experienced trauma.Wrap-around services that address traumatic stress in the person's support network (parents, caregivers, paid support staff, roommates, friends), and that encourage trauma-informed behavior management strategies are likely to enhance outcomes. This reflects Essential Message 6: Utilize an IDD- & trauma-informed person-centered approach to support both the person and their support network.

7.ANSWER:All of the above. Helping a person with IDD who has experienced trauma often involves helping the person and their caregivers strengthen protective factors. This may include helping to restore a sense of safety and preparedness, strengthening informal support networks, and helping caregivers address their own trauma, in addition to traditional individual trauma treatments.This reflects Essential Message 7: Help parents/caregivers, and other professionals in the person's life, strengthen the person's protective factors.

8.ANSWER: False. Nearly all systems of care can play a role in recovery from trauma. Partnerships between agencies and systems can ensure earlier and more sustained access to services. However, careful coordination between services is important to prevent diffusion of responsibility. This reflects Essential Message 8: Partner with agencies and systems to ensure earlier and more sustained access to services.

9.ANSWER: B and C. The use of physical restraints (A) is likely to increase the traumatic stress response of someone who has experienced interpersonal trauma and should be avoided at all costs. Trauma-informed plans should include descriptions of triggers of traumatic responses and methods for grounding and re-establishing a sense of safety (B). Effective person-centered plans also build upon protective factors, such as social support, to increase resilience to the effects of traumatic stress (C). This reflects Essential Message 9: Ensure that trauma-informed person-centered services, treatments, and systems drive the recovery plan.

10.ANSWER: B. Drinking alcohol, using substances, or other strategies that focus on avoidance of symptoms may be effective in the short-term, but risk long-term negative consequences and is not an effective strategy for self-care. There are many ways to deal with symptoms of secondary traumatic stress, vicarious trauma, and burnout that involve balancing our physical, psychological, emotional, spiritual, social, and professional needs. This reflects Essential Message 10: Practice ongoing self-care in order to increase effectiveness in delivering high quality support, services and treatment.

# CERTIFICATE of COMPLETION

## TRAUMA-INFORMED SUPPORTS

THIS ACKNOWLEDGES THAT

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HAS SUCCESSFULLY COMPLETED THE

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### **THRIVING:**

*Helping Adults with Intellectual and Developmental Disabilities Heal and Thrive  
Following Trauma*

12 contact hours in Understanding Need for Trauma-Informed Care; Trauma, Development, and Intellectual and Developmental Disabilities; Understanding the Traumatic Stress Response; Well-being & Resilience; Trauma-Informed Services; and Provider Self Care.

DATE:



Facilitator:

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