Pilot Trauma-Informed Care Learning Collaborative for Organizations Serving People with Intellectual and Developmental Disabilities

Spring 2021 – Summer/Fall 2022
Introduction

Prevalence of Trauma

Trauma is shockingly common in the United States. The landmark Adverse Childhood Experiences (ACEs) study found that in a large, mainstream, and relatively privileged sample, 64% had at least one adverse experience in their childhood and more than 12% had four or more ACEs. It also found that ACEs were closely linked to negative mental and physical health outcomes throughout life.

With people with intellectual and developmental disabilities (IDD), there is general agreement that trauma and adversity is even more common, likely far more common, than with people without IDD. Spencer et al. (2005) found that, compared to children without disabilities, children with moderate to severe IDD were 2.9 time more likely to be emotionally abuse, 3.4 times more likely to be physically abused, 5.3 times more likely to be neglected, and 6.4 times more likely to endure sexual abuse. Sullivan and Knudsen (2000) discovered that 31% of children with IDD suffered child maltreatment compared to 9% of nondisabled children. Experts suggest these number may only scratch the surface given underreporting of abuse by people with IDD.

Trauma-Informed Care

Trauma-informed care (TIC) is an approach to service delivery and education that recognizes the pervasiveness of trauma, realizes its impact on individuals, and responds by establishing practices that meet the needs of trauma survivors. TIC also recognizes that many institutions use control-oriented and punitive practices that, though well meaning, often replicate the environments in which individuals were hurt. TIC, now an international movement, is rapidly being recognized as best practice across sectors including behavioral health, medicine, schools, corrections, courts and probation, early childhood services, and others (SAMHSA, 2014).

Why Trauma-Informed Care with IDD Organizations and Systems

IDD organizations and systems have just begun to grapple with the implications of trauma prevalence for the individuals they support. The last 10 years has seen increased attention paid to trauma and people with IDD including how trauma symptoms manifest, diagnosis, and treatment. However, much less attention has been paid to organization-level interventions including implementation of TIC. Fortunately, some practices commonly used by IDD organizations such as person-centered planning align well with TIC (Kessler, 2014).

TIC is critical for IDD organizations for many reasons including the following.

- IDD organizations inherited the legacy of institutionalization for people with IDD where individuals were not only subjected to punitive environments as the norm, but also suffered trauma directly at the hands of caregivers. The shadow of this history can impact the climate of current day organizations. Policies and practices can unwittingly re-traumatize individuals and evidence suggests that trauma by caregivers is still a concern. A 2004 study found that, over the course of a year, 14% of direct care staff admitted to acts of violence against adults.
with IDD and 35% said they witnessed violence against individuals (Strand, Benzein, & Saveman, 2004).

**TIC is an approach that challenges organizations and systems to examine “business as usual” from the perspective of people that have suffered trauma. It asks them to put in place day-to-day practices that heal rather than exacerbate trauma as well as prevent abuse at the hands of staff.**

- The quality of life for people with IDD so often depends on the quality of relationships with the direct support professionals (DSPs) that work with them. Since de-institutionalization, the responsibilities for DSPs have grown tremendously while the job requirements, pay rate, and on-the-job training have stayed the same. This has often resulted in highly stressful working conditions, widespread burnout, and high rates of turnover (Keesler, 2014).

**TIC views relationships as a central agent of change for trauma survivors; it stresses training of direct care staff; and it emphasizes the critical importance of addressing burnout and promoting staff self-care. Research suggests that TIC implementation decreases burnout and increases rates of staff retention.**

- DSPs have high rates of trauma and childhood adversity themselves. Keesler (2018) found that 75% of DSPs had at least one adverse experience in their childhood (ACEs) compared to 60% in the general population; 30% of DSPs had four or more ACEs compared to 15% in the general population.

**TIC, grounded in an organizational culture characterized by choice, collaboration, safety, and trustworthiness (Harris and Fallot, 2001), is intended to impact both people receiving services and the staff members providing services. Therefore, TIC has the potential to positively impact DSPs well-being and job retention in addition to that of people with IDD.**

- It is common for IDD providers to attribute behavioral problems and symptoms displayed by people with IDD solely to their disability without considering the possibility of other causes such as a history of trauma – a concern referred to as “diagnostic overshadowing.” This can result in an overly simplistic understanding of problem behavior and lead to behavior management plans that are unsuccessful long term because they do not address the root cause of the behavior.

**A core tenet of TIC is that extreme behaviors that providers see as problems are often solutions for traumatized people – the behavior helped them survive abuse, they were adaptive. Providers must understand what need the behavior meets in order to help them meet that need in a way that has fewer negative consequences. For example, a person with IDD that has poor hygiene may not just be avoiding showers. Poor hygiene may have been a way that the individual learned to deter others from sexually abusing them. Interventions therefore must address the sexual abuse as a factor in the behavior to be successful.**
The Traumatic Stress Institute

The Traumatic Stress Institute’s (TSI) vision is a world where organizations and service systems fully embrace and embed trauma-informed care so that all trauma survivors who enter their doors heal and thrive.

To aspire to that vision, our mission is to foster the transformation of organizations and service systems to trauma-informed care through the delivery of whole-system consultation, professional training, coaching and research.

For over 15 years, TSI has supported organizations and service systems across North America to embed TIC into the fabric of their organization using our Whole-System Change Model. Our client agencies range from a small homeless shelter in Cincinnati to a health center on an Indian reservation in Idaho to the child welfare system of Jamaica.

TSI is an internationally recognized pioneer in the area of TIC measurement. In 2016, we co-created the Attitudes Related to Trauma-Informed Care (ARTIC) Scale, one of the first psychometrically validated measure of TIC. It is the most widely used and cited TIC measurement tool available with an estimated 30,000 administrations globally.

Whole-System Change Model to Trauma-Informed Care

Trauma-informed care, by definition, refers to an approach and philosophy for whole systems. Implementation of TIC therefore must impact the whole system. Changing any system is difficult. Transforming systems to TIC is especially challenging because so many of our systems are rooted in traditional models of care that depend on control-oriented and punitive practices.

Isolated interventions to promote TIC such as periodic staff training, urging staff to do self-care, or training clinicians in a trauma-specific treatment such as Trauma-Focused Cognitive Behavioral Therapy (TF-CBT) are important first steps. But, alone, they will not change an organization.

For this reason, TSI designed the Whole-System Change Model to TIC, an intensive 12-24 month process that aims to transform the fabric of organizations or service systems. As the below infographic shows, the components of the model include: leadership engagement; staff training that includes a train-the-trainer method of sustainability; follow-up coaching; and professional development offerings for an organization’s internal trainers. State-of-the-art program evaluation is integrated throughout to monitor progress and demonstrate outcomes to stakeholder.
Risking Connection – Foundational Trauma Training

A core pillar of TSI’s Whole-System Change Model is Risking Connection (RC) training. RC is a foundational trauma training model that has been vetted and refined over the 25 years since its creation. It is unique in several ways:

- It is a philosophy for providing services rather than a treatment technique.
- It is aimed at organizational staff from all disciplines, roles, and levels of training. It is particularly relevant to direct care workers.
- It creates a common language among staff.
- It asserts that relationships are a primary agent of change.
- It stresses that treating traumatized people poses risks to helpers – the risk of compassion fatigue. Therefore, respect for and care of both the person served and staff person are viewed as vital.

RC is a highly interactive, two-day training that organizations adopt as a standard (generally mandated) professional development offering for their staff. RC uses a train-the-trainer model so that organizations can sustain RC staff training indefinitely by having internal credentialed RC Trainers. By joining TSI’s international community, an organization’s RC Trainers benefit from annual continuing education consult groups and webinars.

Learning Collaborative Method

The Learning Collaborative (LC) method, developed by the Institute for Healthcare Improvement (IHI), is a method for spreading and adopting best practice across diverse settings. It uses strategies for implementing and accelerating innovative practice by capitalizing on organizational peer learning, collaboration, and accountability. LCs have been used across a wide variety of healthcare systems and is a highly regarded way of disseminating best practice.
TSI’s Pilot Trauma-Informed Care Learning Collaborative for IDD Organizations

The Pilot TIC LC for IDD organizations is just that, a pilot. The purpose is to gauge interest among IDD organizations in TIC change and to evaluate a change model in the IDD Sector that has been well vetted in other sectors. We see this as a two-way learning process that will inform future TIC offerings for IDD organizations and systems. Since it is a pilot aimed at mutual learning, we have heavily discounted the price.

In the TIC LC, 4 to 6 organizations will implement TSI’s Whole-Systems Change Model, adapting it to their unique setting. They will share planning meetings, coaching calls, and trainings and collaborate as they implement TIC change at their organization. The Pilot LC will be entirely virtual. The TIC LC involves the following components:

Leadership Engagement
To make the change to TIC, leadership at all levels of the organization, from the Board of Directors to line-level supervisors, must fully buy-in and commit to the TIC transformation process. Without this commitment, TIC change will flounder. TSI Faculty engage senior leadership to ensure that they are prepared to dedicate the human and financial resources necessary to successfully implement TIC.

Leaders are actively involved in determining readiness for TIC change, contracting, the organization’s TIC Task Force, leadership meetings, and attendance at trainings.

Trauma-Informed Care Task Force
Each participating organization forms a TIC Task Force that is responsible for overseeing the implementation process. The TIC Task Force must be authorized by senior leadership and have the resources to mobilize and execute the whole system change process. Each organization’s Task Force will meet on its own 2 to 4 times per month. Representatives from each individual Task Force will convene every 4-6 weeks in Learning Collaborative meetings to learn, plan, and share ideas.

Risking Connection 2-Day Basic Training
Each organization will get a certain number of seats at the virtual RC Basic trainings taught by RC Faculty. Trainees in each RC Basic training will be made up of a cross section of the participating organizations. Seats will be assigned based on the size of the organization.

Any staff that the organization selects to be an internal RC Associate Trainer must attend one of these trainings because it is a required pre-requisite for attending the RC Train-the-Trainer. In general, an organization will strategically fill its seats with key leaders and a cross section of other staff deemed critical to the change process.

Risking Connection 2-Day Train-the-Trainer
As noted, each organization will select staff as RC Associate Trainers for their organization. RC Associate Trainers are formally credentialled and have the role of teaching the RC 2-Day Basic
Training internally within their organization. If possible, it is recommended that at least half of an organization’s RC Trainers have an advanced degree in a human service field.

Organization Implementation Planning and Rollout
Each organization will develop a TIC implementation plan unique to their organization. They will present those plans at LC meetings to receive feedback and refine. The plans outline how they will rollout RC training with staff that did not attend the initial RC Basic trainings and new staff in the future. They will also lay out other intervention steps the organization will use to implement TIC. LC meetings will also be used to share progress on implementation with a stress on peer collaboration and accountability.

Program Evaluation/Research
John Keesler, Ph.D., assistant professor at Indiana University, will lead a research study on the pilot Learning Collaborative initiative. The goal of the study is to evaluate whether the initiative results in organizations becoming more trauma-informed and whether being trauma-informed enhances the quality of services and makes individuals served better off. Institutional Review Board (IRB) approval for Human Subjects Research will be obtained from Indiana University prior to the initiative.

Organizations will be required to arrange for the virtual administration of measures to staff at two or three time points during the initiative. Organizations will be responsible for ensuring that a high percentage of staff complete the measures. Researchers will coordinate with staff at each organization such as information technology (IT) professionals to ensure smooth administration of the measures.

Data will NOT be collected from individuals being served by the organization. Organizations will also track metrics that they already routinely collect (i.e., number of program incident reports; restraints; staff turnover) as part of the research. Every effort will be made to ensure that the program evaluation is not overly burdensome.

Professional Development and Recertification for RC Associate Trainers
By completing the RC Train-the-Trainer, RC Associate Trainers join a large community of roughly 400 Trainers across North America. RC Trainers benefit from professional development webinars (offered each year) and recertification (required once every 2 years). The webinars provide cutting edge information about traumatic stress, TIC, organizational change, being an effective trainer, and many others. The recertification is a one-day training that covers updates to the RC training curriculum as well as discussion of special topics related to TIC and TIC implementation.

Fees for these ongoing trainings are not included in the cost of the Pilot Learning Collaborative. The fees are listed below.

Tentative Timeline
Below is a tentative timeline for the LC. LC meetings will occur roughly every 4 to 6 weeks throughout the process. Additional meetings may be added as necessary.
| Months 0-2 | Finalize contracts  
Convene planning and leadership meetings  
Timepoint 1 data collection |
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<td>Months 3-4</td>
<td>Risking Connection 2-Day Trainings</td>
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| Months 6-7 | Risking Connection Train-the-Trainer  
Timepoint 2 data collection |
| Months 7-14 | Implementation Plan development  
Rollout of RC training in organizations  
Rollout of other TIC implementation goals  
Timepoint 3 and/or 4 data collection  
Next steps following LC |

**Who Should Participate**

We are seeking participant organizations that serve children or adults with IDD in school, home support, day support, foster care, employment, coaching, early intervention, and other programs. Serving individuals with IDD must be central to their organization’s mission.

Organizations of any size can participate. However, due to the limited capacity of the Pilot Learning Collaborative, larger organizations may need to target selected programs within the organization for this initiative -- ones representing a smaller number of total staff -- rather than targeting the entire organization.

Here is the reason for this. If a large organization targets all 500 of its staff, but there is only room for 30 staff to attend the initial RC Basic trainings due to limited capacity, it is not realistic for these 30 people to provide enough momentum to effect change in the organization since it has so many staff. The dosage is too small. A large organization may need to select target programs to participate in the initiative and work to implement TIC in those programs only; they are not permitted to train Risking Connection outside the target programs.

If the organization subsequently wants to implement TIC in the rest of the organization, they can contract with TSI separately to expand the initiative. TSI will offer discounted rates for organizations to do this.

**Expectations for Participating Organizations**

1. Commit the necessary staff resources to this intensive system change initiative.
2. Leverage senior leadership buy-in, support, and participation in the initiative.
3. Form a TIC Task Force that meets regularly and is authorized to plan and lead the TIC change initiative within the organization.
4. Have TIC Task Force representatives actively participate in Learning Collaborative meetings throughout the project. In general, meetings will take place every 4 to 6 weeks. Additional meetings may be added.

5. Agree to integrate the 12-hour Risking Connection training into standard professional development offerings for staff.

6. Select staff to attend the 2-Day Risking Connection training led by RC Faculty Trainers.

7. Select staff to attend the 2-Day Risking Connection Train-the-Trainer.

8. Develop and execute a written implementation plan outlining how the organization will rollout RC training and other targeted TIC implementation steps.

9. Participate in the program evaluation for the initiative. This includes:
   a. Working closely with the research consultant and the Traumatic Stress Institute to plan and execute the program evaluation at the organization.
   b. Administering online measures to all staff at the organization at 2-3 time points and follow-up with staff to ensure a high response rate.
   c. Tracking other organizational metrics that are routinely collected.
   d. Using program evaluation reports to make data-based decisions on how to adjust TIC implementation.

10. Budgeting for sustainability costs of RC Trainer professional development and recertification (see fees below).

**Fees**

The below fees represent a steeply discounted rate applicable for this pilot Learning Collaborative only.

**Fees for Participation in the Pilot Learning Collaborative**
- Organizations with 50 or fewer staff: $8000
- Organizations/selected programs with between 50 and 150 staff: $11,000
- Organizations/selected programs with more than 150 staff: $15,000

**Ongoing Fees for RC Trainer Professional Development and Recertification**
- $300-800/year depending on the size of the organization

**Fees for Larger Organizations to Implement TIC Training Beyond the Programs Targeted in the Pilot TIC LC**
- Fees depend on size of the organization. Organizations must recontract with TSI to expand implementation. Normal rates will be discounted.
Applications Process

Because of the limited capacity of the Learning Collaborative (4 to 6 organizations), organizations must submit a brief application to be considered. To download the application template in Word, click here. The application deadline is midnight on March 20, 2021. To view a recording of the Information Meeting about the Learning Collaborative where we discuss the application process, click here.

We wish we could include everyone in this Pilot Learning Collaborative and, again, we hope to offer other Learning Collaboratives in the future. For the Pilot, criteria for selection will include areas such as:

1. Leadership commitment and buy-in toward system change to TIC.
2. General organizational readiness for change.
3. Capacity to collect data.
4. A balance of sizes of participating organizations
5. Diversity of populations served and service types by participating organizations

Faculty Expert Team

See Appendix A below for biographies of the Faculty Expert Team that will lead the Learning Collaborative.

Future TIC Offerings for IDD Organizations and Systems

TSI has made it a strategic priority to support trauma-informed system change for IDD organizations and systems. Future offerings will depend on the success of the Pilot Learning Collaborative and interest from the wider IDD sector. If systems are interested in discussing a Learning Collaborative for organizations and programs in their system alone, please contact us (steveb@klingberg.com).

References


Appendix A

Faculty Expert Team

Steve Brown, PsyD, is the Director of the Traumatic Stress Institute (TSI) of Klingberg Family Centers whose mission is to foster transformation in organizations and systems to trauma-informed care (TIC). A clinical psychologist, he is a primary architect of TSI's internationally recognized Whole System Change Model to Trauma-Informed Care which uses Risking Connection training as its core offering. In 2020, he authored the adaption of Risking Connection to organizations serving people with intellectual and developmental disabilities (IDD). With Dr. Courtney Baker, he developed the Attitudes Related to Trauma-Informed Care (ARTIC) Scale, one of the first and currently the most widely used psychometric measure of TIC. Dr. Brown presents nationally about TIC implementation and measurement and is the co-author of journal articles on those subjects. In addition to being a psychologist, he is a long-time sexuality educator/trainer and author of Streetwise to Sex-Wise: Sexuality Education for High Risk Youth, a sexuality education curricula used internationally by agencies and schools serving high risk youth.

Brenda Bryant, MSW, has been working with people with intellectual and developmental disabilities in behavioral health for the past 20 years primarily doing direct care and program development. At Keystone Human Services (Connecticut), she has been a leader in their implementation of trauma-informed care in residential treatment and clinical services. In 2020, she became a Risking Connection Faculty Trainer for the Traumatic Stress Institute, specializing in training and consultation to IDD organizations. From 2018 to 2020 Brenda served on the Connecticut chapter of NASW Board of Directors and advocated for increased public education about equity and opportunity for individuals with disabilities.

Karyn Harvey, PhD, has worked as a clinician in the field of intellectual disabilities for over 30 years. She has her doctorate in Applied Developmental Psychology from the University of Maryland. Dr. Harvey has published articles about therapeutic interventions with individuals with intellectual and developmental disabilities (IDD), workbooks for individuals with IDD, and two books. Positive Identity Development was published in 2009 and Trauma-Informed Behavioral Interventions in 2011. Her third book, Trauma and Healing will be released in 2021 by AAIDD. She is the director of program development and training for the Park Ave Group practice in Baltimore, MD where she does both individual and group therapy. In addition, she regularly conducts trainings on trauma-informed care and coping with COVID-19 for both state and individual organizations throughout the US and in Canada.
John M. Keesler, PhD, LMSW, is an assistant professor in the School of Social Work at Indiana University Bloomington. He has more than 10 years of practice experience with people across the lifespan who have intellectual and developmental disabilities (IDD). Beginning as a direct support professional, Dr. Keesler spent most of his time working in behavioral health and administration for non-profit organizations prior to pursuing a doctorate in social welfare. With a firm foundation in his practice experience, Dr. Keesler’s research focuses on adversity/trauma, trauma-informed care, and quality of life. In 2014, he published the first article in the scholarly literature promoting the integration of trauma-informed care with services for people with IDD. Since that time, he has continued to conduct relevant and timely research on the substantive area. His research underscores the importance of trauma-informed care as a total system approach to advance the quality of life for people with IDD as well as the professional quality of life for those that support them, namely, direct support professionals. Dr. Keesler has presented his scholarship at local, state, national, and international conferences and published in both national and international journals.