TTAC

NYC Early Childhood Mental Health

Training and Technical Assistance Center

Addressing Trauma-Related Needs of Young Children With Developmental Delays and Disabilities

Presented by Dr. Juliet Vogel

Who We Are

The New York City Early Childhood Mental Health Training and Technical Assistance Center (TTAC), is funded by the NYC Department of Health and Mental Hygiene (DOHMH)

TTAC is a partnership between the New York Center for Child Development (NYCCD) and the McSilver Institute on Poverty Policy and Research

- **New York Center for Child Development** has been a major provider of early childhood mental health services in New York with expertise in informing policy and supporting the field of Early Childhood Mental Health through training and direct practice
- **NYU McSilver Institute for Poverty Policy and Research** houses PeerTAC and the Community and the Managed Care Technical Assistance Centers (CTAC/MCTAC), which offer clinic, business, and system transformation supports statewide to all behavioral healthcare providers

TTAC is tasked with building the capacity and competencies of mental health and early childhood professionals through ongoing training and technical assistance
http://www.TTACny.org

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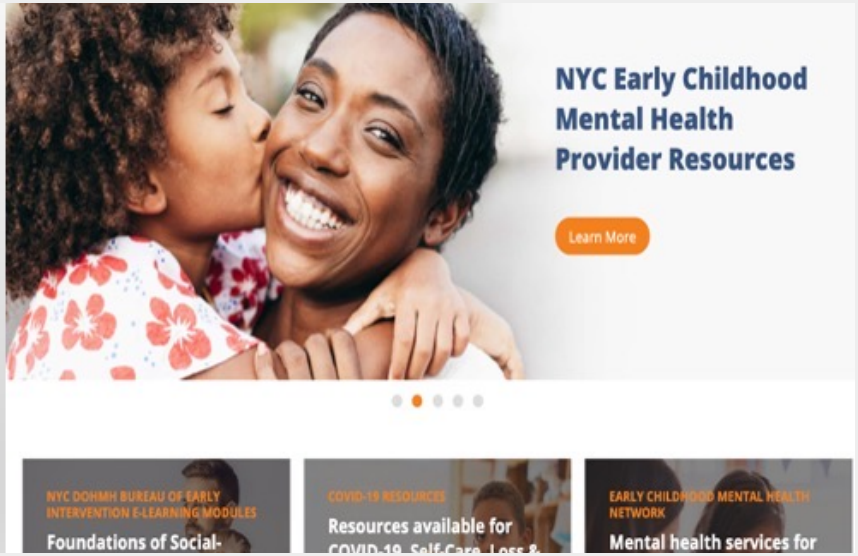
Updated TTAC Website

Explore all the provider resources at ttacny.org



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TTAC Infant and Early Childhood Mental Health (IECMH) Learning Modules are now live!

Two Learning Modules:

- The first module in the series is**the Impact of Early Childhood Adversity (An Overview of the Topic)**
- The second module in the series is **Nurturing Resilience: Supporting Infant and Early Childhood Mental Health**
- CEUs Available upon completion!

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Long Island Jewish Medical Center
Northwell Health®

Addressing Trauma-Related Needs of Young Children With Developmental Delays and Disabilities

Juliet M. Vogel, Ph.D.
Associate Professor, Zucker School of Medicine at Hofstra/Northwell

The STRYDD Center—Supporting Trauma Recovery for Youth with Developmental Disabilities
LIJ Medical Center, Northwell Health System
June 14, 2023

STRYDD Center

Based on work for the Center for Supporting Trauma Recovery for Youth with Developmental Disabilities (STRYDD), Long Island Jewish Medical Center

First National Child Traumatic Stress Network Treatment Adaptation and Dissemination Center to address needs of children with developmental disabilities who have experienced trauma

- Education on trauma needs of children with developmental disabilities
- Tailoring treatments – began with TF-CBT

Thank you to colleagues who have supported this work

- Peter D'Amico, PH.D., ABPP, Director of Child Pschology, Zucker Hillside Hospital and PI for STRYDD grant and the STRYDD team

- Consultants regarding preschool children with trauma:
  - Joy Osofsky, Ph.D.
  - Kay Connors, LCSW-C

And to the children and families who continue to be important teachers

Plan

1. Introduction regarding child trauma
2. Evidence for co-occurrence of trauma and developmental delays disabilities in early childhood
3. Cautions regarding direction of causality
4. A role for early intervention/preschool intervention: special Issues (opportunities and challenges) concerning IDEA PART C
5. Trauma treatment for young children with disabilities

Definition of Trauma for Young Children (DC: 0-5)

- Exposure to a frightening/terrifying event or a series of events
- The infant/young child may experience the event directly, witness it as it occurs to others or learn that it occurred to a significant person in the infant's young child's life

Some types of trauma and examples concerning young children

- Accidents
- Disasters
- Frightening medical procedures

- Exposure to violence
  - Community violence
  - Domestic violence

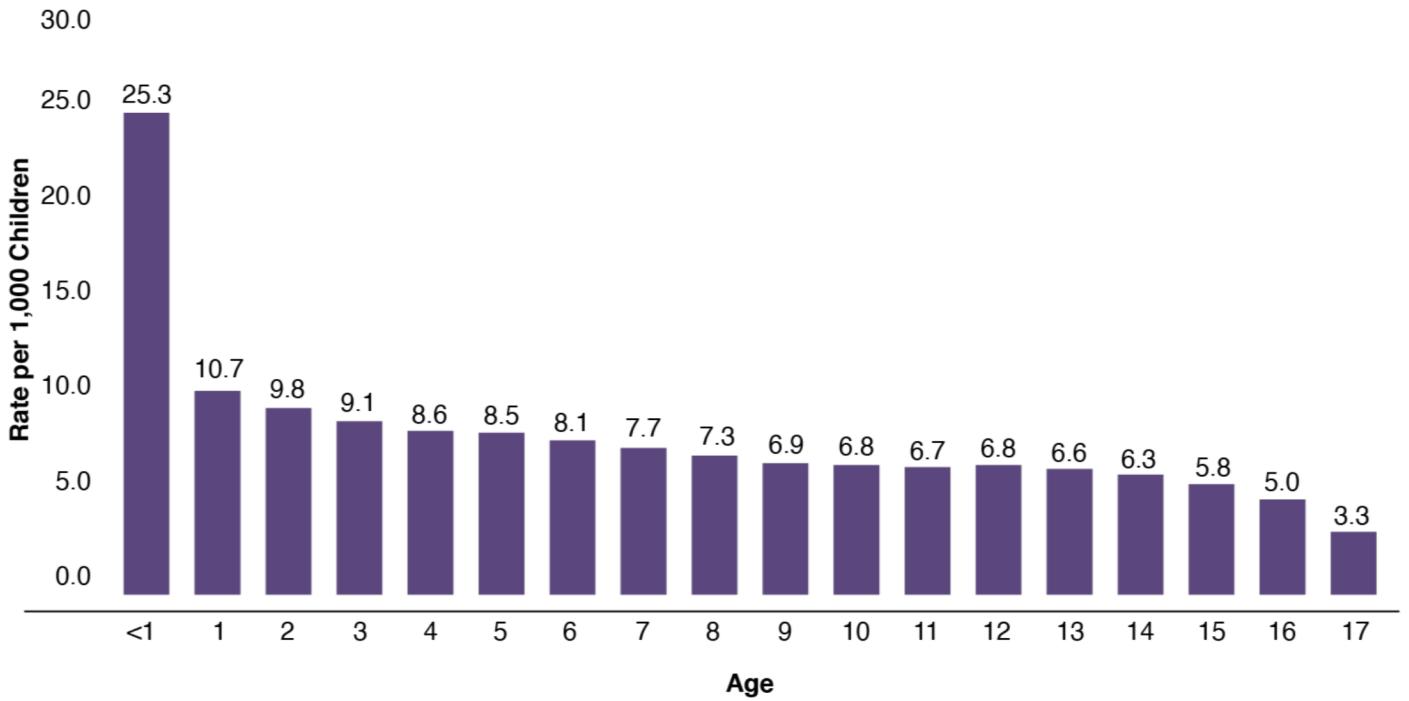
- Maltreatment
  - Neglect
  - Physical abuse/emotional abuse/sexual abuse

- Events can be time limited, part of a cascade of events, recurring/ongoing

Children's Bureau Child Maltreatment Report
Incidence by Age

Exhibit 3–D Victims by Age, 2021

The youngest children are the most vulnerable to maltreatment



Based on data from 51 states. See table 3–5.

Population linkage studies show higher rates of maltreatment for children with disabilities

O'Donnell et al (2010); *Maclean et al. (2017): Western Australia

Maclean: average age of first report 4.8yrs with disability, 4.2 yrs without

*Spencer et al. (2005): West Sussex Area of England

Sullivan & Knutson (2000): Omaha, Nebraska

Average age first report :

preschool for children with language, learning issues

evenly divided between preschool and elementary school for ID

*Attenuated but still higher rated for disabled when one controls for demographic factors

Developmental Assessments of Young Children Referred to Child Welfare: National Surveys of Child and Adolescent Well-Being (NSCAW)

NSCAW I

- Referrals Oct 1999-Dec 2000
- 6228 children, 0-15 yrs
- Oversampled infants
- 93 locations representative of US
- Assessments at baseline, 18 mos, 36 mos, 5-6 years
- interview data at 1 yr

NSCAW II

- Referrals Feb 2008-April 2009
- 5873 children 0-17.5 years
- Oversampled infants
- 82 US counties
- Assessments at baseline, 18 mos, 36 mos

Sources of developmental information, NSCAW I and II

- Information from child welfare workers and caregivers
- Direct assessment for young children included:
  - Bayley Neurodevelopmental Screener (infants)
  - Cognitive: Battelle Developmental Inventory up to age 4, then Kaufman Brief Intelligence Scale subtests
  - Language: Preschool Language Scale
  - Adaptive: Vineland Adaptive Behavior Scales Daily Living

NSCAW High Developmental Risk

2 standard deviations below average (lowest 2%) in one area, or 1.5 standard deviations in 2 or more areas

- cognition
- language
- adaptive behavior

or

established medical condition with high risk of delay

- **Chosen to correspond to criteria for early intervention services in states with stringent requirements**

NSCAW rates of high developmental risk

NSCAW 1:

- initial assessments from 1845 youngsters age 0 to 36 mo **more than 35% were at high developmental risk**:
    - 1.5 % established medical condition
    - 32% delays based on the developmental screens,
    - 2% both (Casanueva et al., 2008).
  - At 18-month follow-up**, 39.2% showed high developmental needs.**

NSCAW II baseline for 3766 children under age 6:

32.2% showed high developmental need (Casaneuva et al 2012)

Multiple pathways of risk

- In work regarding older children, assumption often made that higher rates of trauma result from having a disability

- In NSCAW I, consistency of low developmental scores over time for infants and toddlers with substantiated maltreatment associated with environmental risk factors such as poverty, low education of mother, impaired mother (Scarborough et al, 2009)
  - Biological risk?
  - Environmental risk?
  - Interaction?

- Special issues associated with neglect (see next two slides)

Impact of neglect

- **Neglect is most common type of maltreatment for infants, toddlers, preschoolers in (Child's Bureau, 2023, NSCAW I and II)**

- **Severe neglect associated with significant delays—evidence from long history of studies of impact of depriving institutional care in work by Spitz, Province and Lipton, Skeels & Dye, others but more systematic in Bucharest orphanage studies (see Dozier et al, 2012)**

- **Impact of severe neglect more likely to be reversed if child placed in stimulating environment by about age 2 (timing depends on area of development)** (National Scientific Council on the Developing Child, 2012, Nelson et al, 2019)

Severe neglect and “quasi autism”

For some children with severe neglect, symptoms partially mirroring those of autism may occur (Levin et al 2005; Rutter et al., 1999)

“quasi autism” symptoms may abate to some extent in nurturing environments, but they may have long-term sequelae (Komsta et al., 2015).

Children with disabilities at heightened risk for stressful medical experiences

- **Higher rates of health care needs** (Boulet et al., 2009; Schieve et al 2012)
- **Higher rates of injuries** (Lee et al., 2007; McDermott, et al., 2008),
- **More medical visits (Schieve et al 2012)**
- **More ER visits and hospitalizations (Lindley et al. 2016)**

  (seizures most frequent reason for ER/hospitalization)

Useful web site of health care social stories from Boston Medical Center's Autism Friendly Initiative https://www.bmc.org/visiting-us/autism-friendly-initiative/health-care-social-stories

Early intervention:
The opportunities and challenges of IDEA Part C

- Individuals with Disabilities Education Act (IDEA) Part C : Federal program providing assistance to states for a comprehensive system of early intervention services for infants and toddlers and their families

- Includes children with
  - significant developmental delay (defined by state)
  - diagnosed medical condition likely to lead to a developmental delay
  - A few states include other risk factors that might lead to delays.

- Since Child Welfare Prevention and Treatment Act (CAPTA) of 2003 and IDEA reauthorization in 2004, must include “provisions and procedures” for referral of young chidren with substantiated maltreatment to early intervention

The opportunities regarding Part C

- To expand availability of services
  - for children with substantiated maltreatment and delays to get developmental treatments they need

  - Additional opportunities:
    - as way to offer trauma treatment
    - for coordination of developmental and trauma treatments

  (Gilkerson, et al., 2013)

Challenges regarding Part C
Actual referrals from child welfare

- NSCAW I (1999-2000—before new CAPTA/IDEA legislation):
  - Of substantiated cases, more without high developmental need (16.3%) than those with (12.7%) had an Individual Family Service Plan by 1 year after CW investigation
  - Children with substantiated cases and with higher level of CW involvement more likely to get services
  - level of developmental need at least as high in unsubstantiated cases

  (Casaneuva et al., 2008)

Child Welfare referrals to part C: process evolving

- NSCAW II cases investigated 2008-2009 (4-6 years after new legislation)
  - Referrals to part C remained low (18% of substantiated cases, 12% of unsubstantiated)
  - Referrals unrelated to developmental needs (language, cognition, adaptive behavior) according to NSCAW assessments
  - No significant differences in developmental scores for substantiated versus unsubstantiated cases.

  (Johnson-Motoyama et al, 2016)

  But some subsequent progress—see next slide

Child Welfare referrals to part C: processes evolving

- 2014 survey of state Part C coordinators:
  - 61% said CW refers all children directly to Part C agencies for screening; 30% said CW agency screens
  - Nearly two thirds were fairly confident or very confident that all children under three years with substantiated CW cases screened

  (Shannon, 2021)

- Programs exist in some states that improve communication and build toward integrated intervention (Shannon, 2021; Moses et al., 2016)
- Example of specific collaborative project (Adrihan et al., 2018)

Part C for children involved with child welfare
Some of the challenges

- Interviews and surveys with professionals, families, foster families (e.g. Ward et al., 2009). Some of the issues raised by early childhood education professionals
  - Handling practical situations regarding children in child welfare: e.g. comments by children about their situation, or reactions after visitation
  - Some felt more training needed in dealing with highly stressed families

Consideration of trauma-informed Part C

- Gilkerson and colleagues (2013) provide vision of trauma-informed EI services

  Some of the recommendations
  - Build on EI's values of individualized, family centered planning and intervention, importance of social/emotional wellbeing
  - **Trauma training, consultation, reflective supervision**
  - Some practical issues
    - Trauma screening
    - Considerations when there is known trauma
      - e.g., when separating young children and caregivers for assessment
    - Dealing with impact of trauma on families
    - Usefulness at times of co-treating between developmental specialists and infant mental health specialists (some examples later)

General resources on addressing childhood trauma in early education

- Barlett & Smith (2019) discusses role of early care and education in addressing childhood trauma, describes some specific programs

- Early Childhood Technical Assistance Center's 2022 briefing paper regarding intersection of early intervention and early childhood mental health initiatives
- https://ectacenter.org/topics/iecmh/iecmh-partc.asp

Trauma-related treatment for young children with disabilities
Some examples

- Parent-Child Care (PC-CARE): 6 session dyadic treatment program for families with child 1-10 yrs. Focus: improving parent-child relationship, behavior management Has materials re use with children who have autism or intellectual disability https://pcit.ucdavis.edu/pc-care/pc-care-research/

- ARC Grow—time-limited parenting program based on ARC framework, version for parents of children with developmental disabilities under development (Kinnenberg, personal communication)

- Child Parent Psychotherapy (CPP) Case studies and discussion re application

Child Parent Psychotherapy (CPP)

- Evidence-based trauma treatment
  - for children ages 0 through 5 years
  - who have experienced one or more stressful events
  - are experiencing issues in one or more domains of functioning (behavior , emotional reactions, relationships , development)

- Some key sources:
  - Lieberman, A. F. & Van Horn, P. (2008). *Psychotherapy with infants and young children.* Guilford
  - Lieberman, A. F., Ghosh Ippen, C. & Van Horn, P. (2015). *Don't hit my mommy!* A manual for Child-Parent Psychotherapy with young children exposed to violence and other traumas.(2nd ed.). Zero to Three.

CPP for children with developmental issues

- **Uniquely positioned for tailoring for disabilities:**
  - **Evolution from Selma Fraiberg's work with congenitally blind infants to infant-parent psychotherapy extended by Lieberman and colleagues to child-parent psychotherapy (extended age range, more specific trauma focus)**

- **One series of articles in *Pragmatic Case Studies in Psychotherapy* (2014)**
  - Harley, E.K, et al. (2014). Presents cases of "James" and "Julian." Seen in outpatient clinic in facility that also had interdisciplinary DD program
  - Ghosh Ippen et al. (2014): Chandra Gosh Ippen, Carmen Rosa Norona, and Alicia Lieberman provide commentary
  - Williams et al. (2014). Clinical team provide additional commentary

CPP overview

- Dyadic treatment of child with caregiver(s); premise that the attachment relationship is key resource for young children's ability to deal with stressful events and thus for trauma recovery
- Draws on multiple theoretical orientations including psychodynamic, developmental, trauma, social learning, cognitive-behavioral
- Looks at child and caregivers in a social and cultural context
  - Respects family culture
  - When needed, provides assistance addressing problems of daily living critical to family functioning

CPP phases of treatment

- Foundation: assessment and engagement
  - Forming a working alliance with caregivers
  - Assessing child's issues and functioning
  - Assessing functioning of the dyad
  - Consideration of factors that may influence that functioning including
    - functioning of the caregivers,
    - trauma background /experiences that can impact parents' ability to respond to child
    - problems of daily living impacting caregiving and child well-being

- Core intervention
  - Dyadic sessions. Play based, therapist helps to facilitate understanding within the dyad, helps caregiver's support of child.
  - For pre-verbal children, "speak for the child"
  - Parent guidance; may include separate parent guidance sessions
  - May include coordination with other providers, referral to resources
  - Addressing the traumas: depending on issues, child's development, and circumstances, may or may not do a full trauma narrative

- Termination

CPP is evidence based and manual guided

- 5 clinical studies
- Substantial flexibility in actual activities
- Treatment can be in clinic or in the home. Weekly sessions over a period as long as a year.

Harley's case examples

- Medical trauma: 14 month old with normal development until cardiac surgery at 11 months, then stroke, many seizures, developmental regression. High poverty Latino family, 3 older children, (seen in home)
- DV + ASD: 6 year old with ASD dx, history of exposure to DV by both parents, separations and shifts in parenting; at time of referral raised by father and father's sister.

- Both cases involved:
  - helping parents with their own reactions (James's mother's grief about loss of her healthy son, Juan's father's guilt about his role in the earlier DV)
  - Improving parental understanding of their child's issues – both trauma-related and developmental, developing sense of hope
  - Supporting improved parent-child interaction

(continued on next slide)

Harley's cases (cont)

- Medical trauma: 14 month old with normal development until cardiac surgery at 11 months, then stroke, many seizures, developmental regression. High poverty Latino family, 3 older children, (seen in home)
- DV + ASD: 6 year old with ASD dx, history of exposure to DV by both parents, separations and shifts in parenting; at time of referral raised by father and his sister.

- Key features of both cases (continued):
  - Interdisciplinary consultation for
    - better understanding of child's developmental issues,
    - support on how to facilitate developmentally appropriate interaction
  - Interdisciplinary collaborative work:
    - therapist in EI sessions Case 1; Collaborative sessions with OT (Case 2)
  - Honoring cultural factors
  - Assisting with access to supportive resources

Some general principles

- Some major points from Harley et al. (2014); Williams et al (2014)

  - Therapeutic assessment as an intervention tool
  - Supporting family resilience
  - Supporting access to resources including education, disability services
  - Goal: resume optimal developmental trajectory for the child (not necessarily normal development
  - Consider relevance for children older than 5 with developmental delays

Similarities and differences compared to principles for TF-CBT tailored for IDD

- Similarities
  - Tailor to the child while honoring general principles
  - Pay attention to language and non-verbal supports
  - Pay attention to importance of structure and routines
  - Involvement of caregivers is key
  - May need to coordinate with multiple systems, may include getting assistance with dd assessment and intervention strategies, dd services
  - Taking into account cultural context

- Differences:
  - Central role of attachment
  - Central role of supporting the parent
  - May or may not do trauma narrative
  - Can use when child is pre-verbal/non-verbal

Concluding thoughts

- Opportunities and dilemmas
  - Rewarding but challenging
  - How to get an appropriate workforce?
    - Helpfulness of interdisciplinary teams; transdisciplinary work
    - As needed, getting consultation
      - For trauma therapists: on development, developmental disabilities and disability services
      - For developmental interventionists: on trauma issues and trauma-informed practice
      - For both: on medical issues and their impact

    - In any trauma work, the importance of support and self care