FOR HEALTH CARE PROVIDERS

Pediatric Medical Traumatic Stress

A Comprehensive Guide

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Pediatric Illness, Injury and Traumatic Stress

Children and families are often distressed by:

- sudden or life-threatening illness or injury
- painful or frightening treatment procedures
- just being in the hospital or ED

Most children and parents are able to cope well, with some extra support and with time. Some will have persistent traumatic stress reactions such as Posttraumatic Stress Disorder (PTSD).

Prevalence of Traumatic Stress

- Many ill or injured children, and their families (up to 80%) experience some traumatic stress reactions following a lifethreatening illness, injury, or painful medical procedure.
- It has been reported that between 20 30 % of parents and 15 25% of children and siblings experience persistent traumatic stress reactions that impair daily functioning and affect treatment adherence and recovery.

When they persist, traumatic stress reactions can:

- impair day-to-day functioning
 - affect adherence to medical treatment
 - impede optimal recovery
 - By incorporating an awareness of traumatic stress in their encounters with children and families, health care providers can:
 - minimize potentially traumatic aspects of medical care
 - identify children and families with (or at higher risk for) persistent distress
 - provide anticipatory guidance to help prevent long-lasting traumatic stress

Why A Toolkit?

This toolkit was produced by the Medical Traumatic Stress Working Group of the National Child Traumatic Stress Network (NCTSN) to:

- Raise awareness among health care providers about traumatic stress associated with pediatric medical events and medical treatment, as it may affect children and families.
- Promote "trauma-informed practice" of pediatric health care in hospital settings across the continuum of care and in a variety of settings within the hospital - e.g., from emergency care, to specialized inpatient units, to the ICU.

This compendium of materials is designed for hospital-based health care providers (physicians, nurses, and other health care professionals.) The materials may also be of use to mental health professionals who work in health care settings. The materials provide:

- an introduction to traumatic stress as it relates to children facing illness, injury, other medical events
- practical tips and tools for health care providers, and
- handouts that can be given to parents that present evidence-based tips for helping their child cope

The stories of two children (Tommy — a school-age boy struck by a car, and Maria — an adolescent girl newly diagnosed with cancer,) are presented as part of the toolkit. These composite cases are used to help bring these issues to life and to illustrate ways in which toolkit materials could be useful to providers at various points in the continuum of care.

TOOLKIT MATERIALS	Print Materials	NCTSN Web Site	Other Materials
Pediatric Medical Traumatic Stress — A Comprehensive Guide Resource Lists: • Suggested reading for healthcare providers Guide to Useful Assessment Tools: • Screen for risk of traumatic stress • Assess acute stress reactions • Assess posttraumatic stress symptoms	v	*	
Pediatric Medical Traumatic Stress — Your Guide to Using the Toolkit Effectively	~	~	
Brochure: What Health Care Providers Should Know About Pediatric Medical Traumatic Stress	¥	¥.	
Quick Guides: Distress, Emotional Support, Family, and Quick Screen Pocket Cards	V	۲	PDA Download
Handouts for Parents: At the Hospital: Helping Your Child Cope At the Hospital: Helping Your Teen Cope After the Hospital: Helping Your Child Cope Medical Traumatic Stress: Suggested Resources for Parents	4	~	



TRAUMATIC STRESS REACTIONS

Re-experiencing

- Thinking a lot (unwanted, intrusive thoughts) about the illness, injury, or procedure
- Feeling distressed at thoughts or reminders of it
- Having nightmares and "flashbacks"

Avoidance

- Avoiding thinking or talking about the illness, injury, or hospital experience, or things associated with it
- Displaying less interest in usual activities
- Feeling emotionally numb or detached from others

Hyper-arousal

- Increased irritability
- Trouble concentrating or sleeping
- Exaggerated startle response
- "Hyper-vigilance" always expecting danger

Other reactions

- New fears related to the medical event
- New somatic complaints (bellyaches, headaches) not explained by medical condition
- Feeling in a daze or "spacey"



What Is Traumatic Stress?

Children and parents may have traumatic stress reactions to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences. These traumatic stress reactions can include psychological and physiological symptoms of arousal, re-experiencing, and avoidance (see box.) When a constellation of these symptoms persists and causes distress, the individual may have Posttraumatic Stress Disorder (PTSD).

Children may have other kinds of reactions to illness and injury as well, including behavioral changes or symptoms of depression or anxiety. Whenever providers or parents have any serious concerns about a child's ability to cope with illness or injury, or about emotional and behavioral changes that occur in connection with a medical event, careful assessment of the child, in consultation with an experienced mental health professional, is key.

Persistent Traumatic Stress Reactions

Traumatic stress reactions to medical events are common initially, and not all of these reactions are problematic. For example, in the first few weeks after a difficult or frightening medical event, having frequent intrusive thoughts about what happened may help the individual to process the experience and put it into perspective. For some however, these reactions can be extremely distressing. When they persist, traumatic stress reactions may become disruptive to a child's or parent's everyday functioning and may warrant further attention.

Who is at Increased Risk?

Studies of ill and injured children and their parents show that the occurrence of traumatic stress reactions is more closely related to the person's subjective experience of the event rather than its objective medical severity. We cannot rely on objective indicators of injury or illness severity to tell us which children or parents are most at risk for psychological sequelae. Research studies suggest a range of risk factors for long-lasting traumatic stress reactions, including: pre-existing vulnerabilities; prior behavioral or emotional concerns; traumatic aspects of the medical event; and the child's or family's early reactions to it.

Risk Factors For Persistent Traumatic Stress Reactions

An ill or injured child may be at greater risk for persistent traumatic stress reactions if s/he:

- has had severe early traumatic stress reactions
- · has experienced more severe levels of pain
- is exposed to scary sights and sounds in the hospital
- is separated from parents or caregivers
- has had previous traumatic experiences
- has had prior behavioral or emotional problems
- lacks positive peer support

A parent may be at greater risk for persistent traumatic stress reactions related to his/her child's illness or injury if s/he:

- has had severe early traumatic stress reactions
- has had previous traumatic experiences
- has had prior emotional or mental health problems
- is experiencing other life stressors or disruption
- lacks positive social support



Prevention Model:

Addressing traumatic stress in the pediatric healthcare setting

Clinical / Treatment

Persistent distress or risk factors. Arrange psychosocial and mental bealth support.

Acute distress or a few risk factors present.

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Provide extra support and anticipatory guidance. Monitor ongoing distress and refer if needed.

Targeted

Most children and families are understandably distressed but coping well.

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Universal

Provide general support — help family help themselves. Provide information regarding common reactions. Screen for indicators of higher risk.

Preventing and Treating Traumatic Stress

Health care professionals providing optimal care for ill or injured children and families should incorporate an awareness of traumatic stress reactions that may interfere with the children's health and functioning into their routine clinical encounters. In some cases, traumatic stress reactions can have serious implications for medical outcomes. For example, research studies have suggested that avoidance symptoms (e.g., wanting to stay away from reminders of illness) may interfere with optimal adherence to medical regimens post-transplantation.

It may be useful to think of preventing and treating traumatic stress reactions as a pyramid:

- Universal (at the base): Most children and families need general information and support.
- Targeted (in the middle): A few higher-risk or more distressed children and families need increased support and focused guidance to help them anticipate challenges and to strengthen their coping skills.
- Clinical/Treatment (at the top): Finally, a much smaller group of children and families need more extensive psychosocial support and evaluation or treatment by a mental health professional.

This preventive intervention model suggests that the health care team provide every ill or injured child and family with basic support and information and regularly screen for acute distress and risk factors to determine which children and families might need more support.

Roles for Health Care Providers

Health care providers caring for children in emergency and hospital settings can:

- incorporate an understanding of traumatic stress in their encounters with children and families
- minimize the potential for trauma during medical care
- provide screening, prevention, and anticipatory guidance
- · identify children and families in distress, or at risk, and make appropriate referrals

Assessing and Treating Traumatic Stress Using the D-E-F Protocol:

All health care providers treating children, regardless of discipline, should be "trauma-informed." This means that they should incorporate an understanding of traumatic stress and related responses into their routine encounters with children and families. Trauma-informed health care professionals should be able to provide basic interventions to children and families that will minimize the potential for ongoing trauma and maximize continuity of care. The D-E-F protocol provides a straightforward and reliable method for identifying, preventing, and treating traumatic stress responses at the time of need and within scope of practice. Healthcare providers are experts in treating illness, restoring functioning, and saving lives. After attending to the basics of children's physical health (the A-B-C's), providers can promote their patients' health and recovery by paying attention to the next steps — "D-E-F"

- Reduce DISTRESS
- Promote EMOTIONAL SUPPORT
- Remember the FAMILY

D-E-F PROTOCOL for Assessing and Treating Children and Families with Traumatic Stress

- DISTRESS See pocket card for brief assessment and recommended interventions to address and treat pain, fears and worries, and grief and loss. Recommendations include:
 - · Actively assess and treat pain, using your hospital's protocol.
 - Provide child with information about what is happening and choices regarding treatment decisions when possible.
 - Listen carefully for child's understanding and clarify any misconceptions.
 - Ask about fears and worries.

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- Provide reassurance and realistic hope.
- **EMOTIONAL SUPPORT** See pocket card for brief assessment and recommended interventions to address child's emotional needs, and barriers to mobilizing existing supports. **Recommendations include:**
 - . Encourage parents to be with their child as much as possible and to talk with their child about worries and fears.
 - Empower parents to comfort and help their child.
 - Encourage child's involvement in age-appropriate activities when possible.

FAMILY See pocket card for brief assessment and recommended interventions to address parents' and siblings' distress, family stressors and resources, and needs beyond medical care. Recommendations include:

- Gauge family distress and other life stressors; identify family strengths and coping resources.
- . Encourage parents to use own coping resources or support available at the hospital or in the community.

E QUICK SCREEN See this pocket card to identify and assist those who have traumatic stress symptoms or who are at greater risk for traumatic stress. **Recommendations include:**

- Involve psychosocial staff in a team-based approach for those at higher risk.
- Make referrals to hospital or community-based mental health resources when appropriate.

OTHER See the charts on pages 7-9 for descriptions and information on useful clinical measures for assessing acute and post-traumatic stress symptoms in children and parents, as well as tools for assessing pain and parent coping assistance.

Special Considerations in Assessing and Treating Young Children Using the D-E-F Protocol:

Many infants and young children are hospitalized every year with injuries and serious illnesses. Emerging evidence suggests that traumatic stress is a problem for these children as well. The protocols and materials contained in this Toolkit apply to traumatic stress reactions in infants and young children, but a number of special considerations should be noted.



Assessing Distress

The assessment of distress in infants and young children is based more on observing the child's behavior than on the child's direct report. Although young children can sometimes tell us what hurts or that they are scared, the verbal limitations of young children make behavioral observations crucial. Behavioral changes that may be indicators of significant distress include: agitation, uncontrollable crying, becoming quiet or withdrawn, oppositional or aggressive behavior, marked startle response, or changes in previously achieved developmental milestones. It is particularly noteworthy when any of these behavioral changes occur during medical procedures or when parents/caretakers leave or return.

Emotional Support and Parent Presence

An infant or young child who has a secure emotional attachment to his/her parents or caregivers depends on the support of those individuals during stressful or difficult events. Children who are deprived of this support are likely to exhibit even greater distress. Every effort must be made to keep parents and their hospitalized children together and to assist parents in helping their children during the stressful time of hospitalization.





Young Children's Understanding

Because they are still developing cognitive skills, young children process information differently. For example, many pre-school children associate pain with punishment and may believe they did something wrong when they are in pain, or that they somehow caused their illness or the injury. They can also get mad or frustrated with the medical provider administering a painful procedure. In addition, pre-school children generally do not understand that some losses (such as the death of a family member or a physical disability) are permanent. For any questions about the way that a young patient is processing information or about how to help your patient gain a developmentallyappropriate understanding of what is happening, consult with a developmental specialist (a child psychiatrist or psychologist or a developmental and behavioral pediatrician).

Health Care Providers' Responses to Medical Traumatic Stress in Their Patients

Working with ill and injured children and families can be professionally meaningful and satisfying. However, health care providers treating children and families with challenging traumatic stress symptoms and circumstances can sometimes feel drained, upset, or frustrated. This may be especially true during times of increased workloads or heightened personal stress. As a result, providers can experience conflicts with these families or other medical team members or find themselves too involved in trying to solve the child's or family's problems in an effort to reduce distress. In working with children and families with complex and challenging illnesses or injuries, it is recommended that health care providers routinely:

- Be aware of their own emotional reactions and distress when dealing with distressed families.
- Talk to another team member or supportive other about their emotional reactions.
- Increase self-care (e.g., relaxation, exercise, stress management, etc.) when they begin to see signs of negative effects.

DISTRESS: Useful Measures For Pediatric Medical Traumatic Stress				
NAME OF MEASURE	PURPOSE	DESCRIPTION	HAS BEEN EVALUATED IN:	CURRENT STATUS OF PSYCHOMETRIC EVIDENCE
	SCR	EENING MEASU	RES	
Child Stress Disorders Checklist (CSDC) Screening Form	Brief screen for ASD or PSTD in children/teens	4 item screener completed by parent or clinician about child	Children 7 to 18	Evidence for prediction of later PTSD in hospitalized children
	Contact: G	lenn Saxe, MD <i>Glenn.Sa</i>	uxe@bmc.org	
Screening Tool for Early Predictors of PTSD (STEPP)	Identify recently injured children, and their parents, at higher risk for later PTSD	12 item screener suitable for use in acute medical setting	Children 8 to 17 and their parents	Evidence for prediction of later PTSD in hospitalized injured children and their parents
References: Winston et al. (2003). Screening for risk of persistent post-traumatic stress in injured children and their parents. JAMA, 290 (5): 643-649. Contact: Nancy Kassam-Adams, PhD <i>nlkaphd@mail.med.upenn.edu</i>				
ASSI	ESSMENT OF AC	UTE STRESS DIS	ORDER / SYMPT	OMS
Child Stress Disorders Checklist (CSDC)	Assess ASD symptoms in children/teens	35 item checklist completed by parent or nurse about child	Children 8 to 17	Evidence for reliability, validity
References: Saxe et al. (2003). Child Stress Disorders Checklist: A measure of ASD and PTSD in children. Journal of the American Academy of Child & Adolescent Psychiatry, 42(8): 972-978. Contact: Glenn Saxe, MD Glenn.Saxe@bmc.org				
Acute Stress Checklist for Children (ASC-Kids)	Assess ASD symptoms in children/teens	29 item self-report checklist	Children 8 to 17	Evidence for reliability, validity
Contact: Nancy Kassam-Adams, PhD nlkaphd@mail.med.upenn.edu (Has been translated into Spanish.)				
Acute Stress Disorder Scale (ASDS)	Assess ASD symptoms in older teens	19 item self-report checklist	Primarily validated in adults. Suitable for older teens.	Well-validated adult ASD measure
References: Bryant, R., Moulds, M., & Guthrie, R. (2000). Acute Stress Disorder Scale: A self-report measure of Acute Stress Disorder Psychological Assessment, 12(1), 61-68. Contact: Richard Bryant, PhD <i>rbryant@psy.unsw.edu.au</i>				

NAME OF MEASURE	PURPOSE	DESCRIPTION	HAS BEEN EVALUATED IN:	CURRENT STATUS OF PSYCHOMETRIC EVIDENCE
ASSESSME	ENT OF POSTTRA	AUMATIC STRES	S DISORDER / S	ΥΜΡΤΟΜS
Child Stress Disorders Checklist (CSDC)	Assess PTSD symptoms in children/teens	35 item checklist completed by parent or nurse about child	Children 7 to 18	Evidence for reliability, validity
	e et al. (2003). Child Stre urnal of the American Acaa Contact: G		t Psychiatry, 42(8): 972-9	
Child PTSD Symptom Scale (CPSS)	Assess PTSD symptoms in children/teens	24 item self-report checklist	Children age 8 to 15	Evidence for reliability, validity
	ld PTSD Symptom Scale	nical Child Psychology, 30	ion of its psychometric p (3), 376-384.	
Re Psychometric	ferences: Blanchard, E., Jo properties of the PTSD (ract: Hitchcock Foundatio	ones-Alexander, J., Buckle Checklist (PCL). <i>Behavio</i> r	ey, T., & Forneris, C. (19 r <i>Research and Therapy</i> , 34	96). 4(8), 669-673.
PAIN ASSESSMENT				
Faces Pain Scale - Revised	Assess children's pain.	Child chooses from scale of 6 faces scored as 0 to 10.	Children age 4 to 16	Well-validated child pain measure

EMOTIONAL SUPPORT: Useful Measures For Pediatric Medical Traumatic Stress				
NAME OF MEASURE	PURPOSE	DESCRIPTION	HAS BEEN EVALUATED IN:	CURRENT STATUS OF PSYCHOMETRIC EVIDENCE
SCREENING MEASURES				
Hospital Emotional Support Form	Brief clinical assessment to aid parents in providing coping assistance to child	12 item questionnaire	Not applicable	Not applicable
Contact: Glenn Saxe, MD Glenn.Saxe@bmc.org				

FAMILY: Useful Measures For Pediatric Medical Traumatic Stress				
NAME OF MEASURE	PURPOSE	DESCRIPTION	HAS BEEN EVALUATED IN:	CURRENT STATUS OF PSYCHOMETRIC EVIDENCE
ASSESSME	NT OF PARENTS	S' ACUTE STRES	S DISORDER / S	Y M P T O M S
Acute Stress Disorder Scale (ASDS)	Assess ASD symptoms in adults	19 item self-report checklist	Adults (age 17 and over)	Well-validated adult ASD measure
References: Bryant, R., Moulds, M., & Guthrie, R. (2000). Acute Stress Disorder Scale: A self-report measure of Acute Stress Disorder. <i>Psychological Assessment</i> , 12(1), 61 - 68. Contact: Richard Bryant, PhD <i>rbryant@psy.unsw.edu.au</i>				
ASSESSMEN	ASSESSMENT OF PARENTS' POST-TRAUMATIC STRESS DISORDER / SYMPTOMS			
PTSD Checklist (PCL)	Assess PTSD symptoms in adults	17 item self-report checklist	Adults (age 18 and over)	Well-validated adult PTSD measure
References: Blanchard, E., Jones-Alexander, J., Buckley, T., & Forneris, C. (1996). Psychometric properties of the PTSD Checklist (PCL). Behavior Research and Therapy, 34(8), 669-673. Contact: Hitchcock Foundation (603) 653-1230 (Has been translated into Spanish.)				

SUGGESTED READING FOR HEALTH CARE PROVIDERS

Overview Articles

Bronfman ET, Biron Campis L, Koocher GP. Helping children to cope: Clinical issues for acutely injured and medically traumatized children. *Prof Psychol Res Pr* 1998;29:574-81.

Horowitz L, Kassam-Adams N, Bergstein J. Mental health aspects of emergency medical services for children: Summary of a consensus conference. *J Pediatr Psychol* 2001;26:491-502. (Published concurrently in Acad Emerg Med 2001;8:1187-96.)

Kassam-Adams N, Fein J. Posttraumatic stress disorder and injury. Clinical Pediatric Emergency Medicine 2003;4:148-55.

Kazak A. Comprehensive care for children with cancer and their families: A social ecological framework guiding research, practice and policy. *Children's Services: Social Policy, Research and Practice* 2001;4:217-33.

Landolt MA, Vollrath M, Ribi K, Gnehm HE, Sennhauser FH. Incidence and association of parental and child posttraumatic stress symptoms in pediatric patients. *J Child Psychol Psychiatry* 2003;44:1199-1207.

Saxe G, Vanderbilt D, Zuckerman B. Traumatic stress in injured and ill children. *PTSD Research Quarterly* 2003;14:1-3. Available at www.ncptsd.org/publications/rq/rq_list.html

Stoddard F, Saxe G. Ten year research review of physical injuries. J Am Acad Child Adolesc Psychiatry 2001;40:1128-45.

Stuber ML, Shemesh E, Saxe GN. Posttraumatic stress responses in children with life-threatening illnesses. *Child Adolesc Psychiatr Clin N Am* 2003;12:195-209.

Zatzick D, Roy-Byrne P. Developing high-quality interventions for posttraumatic stress disorder in the acute care medical setting. *Semin Clin Neuropsychiatry* 2003;8:158-67.

Studies: Assessment /Intervention

Kazak, A., Alderfer, M., Streisand, R. SImms, S., Rourke, M., Barakat, L., Gallagher, P. & Cnaan, A. Treatment of posttraumatic stress symptoms in adolescent survivors of childhood cancer and their families. *J Fam Psychol* 2004; 18(3) 493-504.

Kazak AE, Cant C, Jensen MM, McSherry M, Rourke MT, Hwang W-T et al. Identifying psychosocial risk indicative of subsequent resource use in families of newly diagnosed pediatric oncology patients. *J Clin Oncol* 2003;21:3220-5.

Melnyk BM, Alpert-Gillis L, Feinstein NF, Crean HF, Johnson J, Fairbanks E, et al. Creating opportunities for parent empowerment: Program effects on the mental health/coping outcomes of critically ill children and their mothers. *Pediatrics* 2004;113;e597-e607.

Robert R, Blakeney P, Villarreal C, Rosenberg L, Meyer WJ. Imipramine treatment in pediatric burn patients with symptoms of Acute Stress Disorder: A pilot study. *J Am Acad Child Adolesc Psychiatry* 1999;38:873-82.

Winston FK, Kassam-Adams N, Garcia-España JF, Ittenbach R, Cnaan A. Screening for risk of persistent posttraumatic stress in injured children and their parents. *JAMA* 2003;290:643-9.

Studies: Prevalence and Etiology

Injury

Daviss W, Mooney D, Racusin R, Ford J, Fleischer A, McHugo G. Predicting posttraumatic stress after hospitalization for pediatric injury. *J Am Acad Child Adolesc Psychiatry* 2000;39:576-83.

Fein J, Kassam-Adams N, Gavin M, Huang R, Blanchard D, Datner E. Persistence of post-traumatic stress in violently injured youth seen in the Emergency Department. *Arch Pediatr Adolesc Med* 2002;156:836-40.

Saxe G, Stoddard F, Courtney D, Cunningham K, Chawla N, Sheridan R, et al. Relationship between acute morphine and the course of PTSD in children with burns. *J Am Acad Child Adolesc Psychiatry* 2001;40:915-21.

Winston FK, Kassam-Adams N, Vivarelli-O'Neill C, Ford J, Newman E, Baxt C, et al. Acute stress disorder symptoms in children and their parents after pediatric traffic injury. *Pediatrics* 2002;109:e90.

Zink KA, McCain GC. Posttraumatic stress disorder in children and adolescents with motor vehicle-related injuries. *J Spec Pediatr Nurs* 2002;8:99-106.

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Kassam-Adams N, Fein J. Posttraumatic stress disorder and injury. Clinical Pediatric Emergency Medicine 2003;4:148-55.

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Robert R, Blakeney P, Villarreal C, Rosenberg L, Meyer WJ. Imipramine treatment in pediatric burn patients with symptoms of Acute Stress Disorder: A pilot study. *J Am Acad Child Adolesc Psychiatry* 1999;38:873-82.

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Saxe G, Stoddard F, Courtney D, Cunningham K, Chawla N, Sheridan R, et al. Relationship between acute morphine and the course of PTSD in children with burns. *J Am Acad Child Adolesc Psychiatry* 2001;40:915-21.

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Medical Traumatic Stress:

SUGGESTED READING FOR HEALTH CARE PROVIDERS

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Noyes, J. (1999). The impact of knowing your child is critically ill: a qualitative study of mothers' experiences. *J Adv Nurs* 29: 427-435.

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Young GS, Mintzer LL, Seacord D, Casteneda M, Mesrkhani V, Stuber M. Symptoms of posttraumatic stress disorder in parents of transplant recipients: Incidence, severity, and related factors. *Pediatrics* 2003;111:e725-31.

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About the National Child Traumatic Stress Network

The National Child Traumatic Stress Network (NCTSN) works to raise the standard of care and improve access to services for traumatized children, their families, and communities throughout the United States. Under the leadership of the U.S. Department of Health and Human Services, the Substance Abuse and Mental Health Services Administration (SAMHSA), and the Center for Mental Health Services (CMHS), the NCTSN seeks to advance effective interventions and services to address the impact of traumatic stress. The Network is comprised of more than 50 centers across the United States including universities, hospitals, clinics, community-based mental health centers, and other organizations that serve traumatized children and their families.

The NCTSN Medical Traumatic Stress Working Group

The key to the success of the NCTSN is collaboration among its centers with established areas of expertise. The Medical Traumatic Stress Working Group is comprised of experienced medical and mental health clinicians working to advance the understanding and treatment of traumatic stress associated with medical events and medical treatment as it affects children and families.

This project was funded by the Substance Abuse and Mental Health Services Administration (SAMHSA), U.S. Department of Health and Human Services (HHS). The views, policies, and opinions expressed are those of the authors and do not necessarily reflect those of SAMHSA or HHS.



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