

NCCTS Leadership:

The Core Data Set

The National Center for Child Traumatic Stress (NCCTS) is leading an effort to systematically collect data on child trauma and treatment throughout the National Child Traumatic Stress Network (NCTSN). The Core Data Set was developed as a central part of the mission and vision of NCCTS, which seeks to raise the standard of care for children who have experienced trauma. Through the strong collaborative efforts of NCTSN members, this effort will help the child trauma field identify which treatments work best for specific types of child trauma. The NCCTS/NCTSN Core Data Set provides data related to clinical evaluation, evidence-based interventions, service utilization, and provider training. It stands to serve as a powerful tool to help guide the child trauma field for years to come.

The NCCTS/NCTSN Core Data Set was the first collection of behavioral health data to include a set of forms and assessment measures designed to systematically capture important demographics, trauma exposure, client functioning, treatment, and services information for youth and families affected by trauma. The Core Data Set standardizes the way important data is collected, providing a set of standardized outcome measures across all centers, and setting a consistent time frame and protocol for collecting the information. Additionally, the Core Data Set has several real-time reporting features that can be used to track and monitor treatment progress, as well as administrative reports that can be used for critical sustainability efforts.

NCCTS staff provide administrative and scientific leadership as well as technical expertise for NCTSN in activities related to data collection and utilization. NCCTS staff manage the data contributed by all NCTSN centers, and implement the appropriate methods for evaluating treatment outcomes and health service delivery and utilization. NCCTS provides guidance and direction regarding data definition, collection, and management, combining different sources of data, selecting appropriate assessment and measurement tools, and determining appropriate research methods and strategies for data analysis. NCCTS staff also provide coordination for, and technical assistance related to, data management and analysis. NCCTS develops, implements, and maintains procedures for collecting and analyzing outcomes and services assessment data.

The information collected as part of the Core Data Set:

- Provides a valuable resource for assessment, treatment planning, and ongoing evaluation of client progress and functioning
- Provides a mechanism to answer program evaluation questions that are part of individual centers' and network-wide Quality Improvement initiatives
- Offers a way to capture the overall value of the network in terms of improving care for traumatized youth and offering information to policymakers, health care professionals, and other stakeholders

Preliminary analysis of the data collected to date show that children get better with the right treatment. In addition, the Core Data Set's bi-directional data flow (core data is shared in turn with contributing sites) is helping improve clinical practices and quality of services provided to children and adolescents who have experienced trauma.

These data help to answer some key questions in the field of child traumatic stress. For example, the data continue to clarify the types of trauma children experience, and the relationship between trauma, mental health problems, and "real world" problems (such as school failure) in children and adolescents. Clinicians may use the data to make informed decisions about treatment planning and share information with parents and caregivers about their children's symptoms and progress in treatment.

The NCCTS/NCTSN
Core Data Set helps
clinicians make
informed decisions
about treatment.

Key Accomplishments and Results

The NCCTS/NCTSN Core Data Set was the first data collection effort of its kind. Under the leadership of NCCTS, the Core Data Set has exceeded initial expectations for its use while continuously expanding to meet the changing and diverse needs of NCTSN. To date, the Core Data Set has:

- Compiled data on over 10,000 children from more than 50 current and former NCTSN sites and affiliates
- Developed real-time reports that clinicians can use to enhance clinical practice when working with children and family members. These reports include summaries and graphics to help clinicians and family members track progress over time
- Demonstrated clinically and statistically significant improvements in emotional outcomes (e.g., depression, anxiety, PTSD) and behavioral outcomes (e.g., conduct problems, aggression, and rule-breaking). Initial analyses on functional impairments suggest a 60% success rate of treatment for traumatized children and adolescents
- Enhanced sites' capacity to administer and score standardized assessments, which has been instrumental in increasing the use of evidence-based treatments and promising practices and improving overall quality of care

The Core Data Set

Vision for the Future

NCCTS will continue to collaborate with NCTSN Centers and the NCTSN Data Operations Advisory Committee to make enhancements to the Core Data Set, including expansion to include data relevant to new populations (e.g., very young children, refugees, military families) as well as new standardized assessment measures for grief, depression, and substance use.

In addition, NCCTS will:

- Continue to develop and utilize new technologies to enhance data reporting to include more visual reports and benchmarking tools
- Make available “de-identified” aggregate data sets for analyses to answer key clinical, policy, and research questions in the field of child traumatic stress
- Share strategies to make the data set (of more than 6,000 variables for each of the 12,000 cases are being developed) more user-friendly
- Complete and disseminate publications on key findings that will help advance the field of child traumatic stress
- Continuously monitor and enhance the clinical utility of the data set so that it remains relevant and responsive to the needs of users while raising the standard of clinical care for all children and families at NCTSN centers