

OPPORTUNITY – LOST OR FOUND?
REDUCING CRIME AND RECIDIVISM IN
YOUTH WITH TRAUMATIC BRAIN INJURY (TBI)

**A Guide to Resources to Address
TBI within Juvenile Justice Systems in
the United States**



*How is traumatic brain injury an issue in juvenile justice systems?
What actions can juvenile justice systems take to address this problem?
What resources are available for help in taking action?*

Mount Sinai Injury Control Research Center
Department of Rehabilitation and Human Performance
Icahn School of Medicine at Mount Sinai, New York, NY
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Susan L. Vaughn, M.Ed.
Margaret Brown, Ph.D.
Wayne A. Gordon, Ph.D.

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Mount Sinai Injury Control Research Center (MS-ICRC)

Department of Rehabilitation and Human Performance
Icahn School of Medicine at Mount Sinai
One Gustave Levy Place, Box 1240
New York, NY 10029-6574



**Mount
Sinai**

Foreword

OPPORTUNITY LOST? OR OPPORTUNITY FOUND?

*Joe was admitted to a youth detention center after being charged with simple assault. After several violations of the conditions of his probation, he was placed in a residential facility for six months. He screened positive for traumatic brain injury (TBI) at intake, when in response to **screening questions**, he and his mother reported that he had sustained three sports-related concussions and one more serious suspected brain injury related to a car crash. Although only one involved a brief loss of consciousness, all four caused concussion-related persisting symptoms, and his school grades subsequently suffered. Once **identified** by the center as having sustained four TBIs, with related symptoms, he received an **assessment** to identify his specific challenges; it was conducted by the detention center’s consulting psychologist with expertise in TBI. (More to follow . . .)*

“Opportunity lost” seems an apt characterization of many juvenile justice systems (JJSs) in the United States, in terms of learning about and addressing the needs of youth with TBI under their jurisdiction. With some exceptions, at this time, JJSs simply aren’t aware of or dealing with TBI, including being unaware of what their options might be in response to the unmet needs of youth with TBI. One type of explanation that we hear is that “because there is not enough funding for basic JJS services to begin with, we simply can’t deal with another demand for potentially costly programming, especially without the necessary expertise or resources.”

The reality is, however, that this “opportunity lost” with respect to youth offenders with TBI is simply the most recent one in a long history of failures to act on their behalf, including inaction by and from the three primary elements shaping the childhood of these youths – family, health care providers and schools. Likely, none of them succeeded in responding fully or appropriately to the brain injury(ies) that

preceded the youth’s first foray into crime. The child’s one or more TBIs may not have been fully dealt with by the child’s family (which in some cases is the source of abuse leading to brain injury), by the health care system (perhaps unaware of the need for or availability of more or different treatments than may have been provided) and/or by the child’s school (which may fail to see the need for systematic yearly screening for TBI or even for providing accommodations for children with known TBI returning to school after being hospitalized with a brain injury). Whatever the cause or reason, the child’s needs were not adequately addressed before his/her acting out to the point of juvenile justice involvement. And, these needs will likely remain unaddressed, fully or in part, within most JJSs.

The problem for children and youth who experience one or more **TBIs** is that such injuries – **especially when severe or repeated – typically lead to changes in cognitive, emotional and behavioral functioning that typically persist over time.** For example, a TBI may trigger

changes such as reduced memory, attention, concentration, judgment, decision-making and/or impulse control – all of which may contribute to poor choices that result in legal offenses and violations. And, in fact, having a **TBI is strongly related to crime**. Research tells us that, **compared to those without a brain injury, youth with TBI commit crimes at an earlier age, commit more violent crimes and commit more crimes** (Williams et al., 2010, 2018).

Not only can TBI be devastating to a child's functioning, **TBI is also highly prevalent** amongst juvenile justice-involved youth. The best estimate, based on a systematic review of the literature the MS-ICRC conducted (Dijkers & Seger, submitted for publication), is that **an average of 44% of offenders across diverse JJ settings have experienced one or more TBIs**.

*Based on Joe's evaluation, he received specific **TBI-related supports** to help with school and was **referred** to the state vocational rehabilitation program for **transitional services**. Staff there engaged him in a **work-based learning experience (WBLE)** at a local store, via WIOA (the Workforce Innovation and Opportunity Act) Pre-Employment Transition Services. The juvenile detention staff **drove him to work** each day, where his **job coach** met him to **train him** in strategies to compensate for his impairments, so that he could do a better job. The employer was pleased with Joe's performance and, upon his release from the detention center, arranged for him to work at another store near his home, part-time, while he finished high school.*

The opportunity within JJSs is huge – to break the chain of events triggered by TBI, first by **identifying the problem**, i.e., TBI, through systematic screening, preferably at the youth's first encounter with the JJS, and then **providing simple accommodations and services** to help youths with TBI cope better within the system and to live healthier lives afterwards – thereby, **reducing crime and recidivism**.

Despite the realities of TBI and the inadequate responses of families, and of the health care and educational systems, as well as of JJSs, **there are ways to help** youth with TBI, for example, teaching them techniques for better regulating their emotional outbursts, or better ways of coping with the memory problems that may get in the way when they are asked to follow a schedule in a residential placement or while on parole. Similarly, making accommodations within JJS settings can also be used to address the youth's memory problems (as one example) – such as by training staff to understand the need for making sure, when youth have a TBI, that activities planned for them are recorded in a daily diary that they have been trained to use, rather than staff's "saying it once" and assuming that "once is sufficient".

Joe illustrates how making relatively simple changes within a JJS can achieve good outcomes. Like many juveniles with TBI, prior to JJS-involvement, **at school** Joe had not been identified as having had a TBI and had not received educational supports for addressing his TBI-related cognitive and behavioral deficits, resulting in poor learning and low grades. Similarly, **his family** had not known that the problems that followed his injuries could be addressed,

and so they failed to obtain appropriate services for him. And, **the hospital** that treated Joe after the car crash failed to educate him and his family about challenges that could remain, or even newly emerge, after discharge home.

These **lost opportunities** left Joe without the tools he needed to become and remain aware of his behaviors and then to take action, so that he could prevent the aggressive behaviors triggered by TBI from taking charge, leading him to commit a chargeable offense, an assault. Joe's story demonstrates a JJS breaking into the chain of negative consequences that followed his TBIs: **an opportunity found**. We will not pretend that interventions within the JJS will

solve all of Joe's (or any youth's) problems. After all, **youths with TBI return to their old environment post discharge**, which may give consistent signals to the effect that crime is an acceptable way of life. But the JJS can give the Joes of the world the tools they may choose to use when they return to their communities, allowing them to run with the opportunity the JJS has created.

The aim of this document is to provide guidance on how JJSs can turn opportunities lost into opportunities found. It is based on research evidence, expert opinion and our interviews with staff who implemented programs responsive to the needs of youth with TBI within JJSs in several U.S. states.

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We very much appreciate the input of our colleagues at the MS-ICRC who have contributed to this work. We especially thank Marcel Dijkers, Ph.D., and Madison Seger, M.A., for their work on the systematic reviews of the literature that we have drawn upon herein, as well as Maria Kajankova, Ph.D., and Megan Putnam, Ph.D., for their interviews of state grantees of the Administration for Community Living's Traumatic Brain Injury Partnership Program and for providing vital input throughout the development of this guide. Also, we are especially grateful to the TBI State Partnership Program grantees who shared with us their experiences in establishing programs of screening and services for youth (and adult) offenders within justice systems in 13 states, as well as for many of them providing feedback to us on a draft of this document. Finally, we thank the National Association of State Head Injury Administrators for posting this Guide and related materials on its website and distributing such materials to national and state agencies and organizations.

Table of Contents

| | |
|--|-----------|
| Foreword | i |
| Acknowledgements | iv |
| Table of Contents | v |
| I. OVERVIEW | 1 |
| Introduction to the Guide | 1 |
| Summary of State and Federal Policy Implications | 2 |
| II. BACKGROUND | 3 |
| What is a TBI? | 3 |
| Defining the Problem for Juvenile Justice Systems | 3 |
| How Prevalent is TBI in Juvenile Justice Systems? | 5 |
| TBI Services and Treatments | 5 |
| State and Federal TBI Programs | 6 |
| A Comprehensive Model of Screening and Services | 7 |
| The HRSA “Barriers to Services” Model | 9 |
| State Federal TBI Grantees Focusing on JJ/Corrections: Overview | 11 |
| III. STEPS FOR ADDRESSING TBI IN JUVENILE JUSTICE SYSTEMS | 13 |
| Developing the Program Framework and Building Support | 13 |
| • Introduction | 13 |
| • Laying the Groundwork: Awareness and Education | 13 |
| • Identifying Leadership | 13 |
| • Planning and Implementation | 15 |
| • TBI Resources (see also Section V, pp. 31-33) | 17 |
| Programmatic Elements | 18 |
| • Screening for TBI | 18 |
| • Assessment | 20 |
| • Training | 22 |
| • Interventions and Accommodations for TBI-related Disabilities | 23 |
| • Community Re-entry/Integration: Information & Referral; and Coordination of Resources | 25 |
| Financial Resources | 26 |
| Data and Program Evaluation | 27 |
| IV. SUMMARY AND POLICY IMPLICATIONS | 28 |
| Overview of Implications at the State Level | 28 |
| Implementation of New Programming | 28 |
| Program Elements | 28 |

| | |
|--|-----------|
| Administration | 29 |
| Program Policies | 29 |
| Funding | 29 |
| V. RESOURCES | 31 |
| General Information on TBI | 31 |
| General Information on TBI and Criminal/Juvenile Justice | 31 |
| Activities of TBI State Partnership Grantees (Criminal/Juvenile Justice) | 31 |
| Program Components: Screening | 32 |
| Program Components: Needs Definition, Assessment, Treatments | 33 |
| Children and Adolescents Service System Programs (CASSP) | 33 |
| Education | 33 |
| VI. APPENDICES | 34 |
| References | 34 |
| Acronyms/Abbreviations | 35 |
| Definitions and Terminology | 36 |
| • Juvenile Justice-Related Terminology | 36 |
| • TBI- and Service-Related Terminology (State and Federal) | 40 |
| National/State Associations | 41 |
| Federal Agencies | 42 |
| Prevalence of TBI within JJSs: Methodological Issues | 42 |

I. Overview

INTRODUCTION TO THE GUIDE

The aim of this document is to provide guidance on how state juvenile systems can turn “opportunities lost” into “opportunities found” by better addressing the needs of youth with traumatic brain injury (TBI) who may have been undiagnosed or misdiagnosed.

What expertise and experience do we bring to the task of providing credible guidance? First, the “data” we have drawn upon includes evidence from all of the research that has been done on efforts to identify TBI and to provide responsive services to JJ-involved youth with TBI, including our own research, and focusing on experiences in 13 states receiving federal grants to conduct such work. And, second, we have read, listened to and evaluated this information and evidence through two sets of eyes and perspectives: that of state governance and that of TBI research and clinical experience.

The senior author of this guide, Susan L. Vaughn, M.Ed., is the Director of Public Policy for the National Association of State Head Injury Administrators (NASHIA). She brings to the table extensive experience in working with TBI administrators and other staff of agencies responsible for TBI-focused activities within each of the 50 states, as well as nearly 30 years of experience working in state government. Representing a different perspective are Wayne A. Gordon, Ph.D., and Margaret Brown, Ph.D., who are veteran researchers focused on community-based cognitive and behavioral rehabilitation of people with TBI. Dr. Gordon is the director of and Dr. Brown is consultant to the **Mount Sinai Injury Control Research Center (MS-ICRC)**, at the Icahn School of Medicine at Mount Sinai, supported by a grant from the **Centers for Disease Control and Prevention**. The MS-ICRC is the guide’s publisher.

The catalyst for the MS-ICRC’s initial interest in the **intersection of juvenile justice and TBI** were two people in Texas who were involved with TBI and juvenile justice and separately reached out to us in 2011-12 to seek our assistance. First, the Director of Probation Services of the El Paso County Juvenile Justice Center, Kim Shumate, M.A., asked for help in adapting for juveniles our adult TBI group treatment program (called STEP). She had heard us describe the program’s success at a conference, and she wanted to try it with youths in her Center. Together with Ms. Shumate we adapted STEP (the youth version is called Y-STEP), and then the MS-ICRC formally evaluated Y-STEP’s use in El Paso. Separately, Betty Beckworth, Ph.D., the then director of the Texas Office of Acquired Brain Injury, asked us to train JJS staff in Texas at both state and county levels to screen youth under their jurisdictions for TBI.¹ We carried out these activities through the CDC’s MS-ICRC funding.

¹ A publication of the results of the evaluation of the Y-STEP program is in preparation by the MS-ICRC. The results of screening for TBI have been published (Gordon et al, 2017), and this report is referenced on p. 34. We appreciate the efforts both of Ms. Shumate in El Paso and her staff in developing, implementing and evaluating Y-STEP, and of the current director (Dr. Princess Katana) and her predecessor (Ms. Beckworth) in the Texas Office of Acquired Brain Injury, who were key to the success of the screening program under their jurisdiction. A presentation on both projects has been prepared by the Texas Office of Acquired Brain Injury: <http://cmhconference.com/files/presentations/28th/s68-1.pdf>

From these two experiences in Texas, the MS-ICRC came to understand first-hand both the **high prevalence of TBI in JJS-involved youth** and that **a TBI rehabilitation approach has potential utility in improving functioning, as a means of reducing youth violence/crime and recidivism.**

Several years later, the MS-ICRC is continuing its focus on JJS-involved youth with TBI, with the **goal of strengthening efforts in the United States. to identify TBI in this population and to provide identified youth with needed services.** This guide to resources is one component in addressing this goal².

This guide has drawn upon the MS-ICRC's recent work in **identifying "best practices" for screening and providing services to youth offenders with TBI**, specifically: (1) two **systematic reviews** of the published literature, on prevalence and comorbidities of juvenile justice-involved youth, that the MS-ICRC is now concluding (Dijkers & Seger, submitted). In this process, we reviewed **all published literature** on the intersection of TBI and juvenile justice; and (2) from **interviews we conducted with colleagues** in 13 states who are addressing TBI (or have in the past) among youth in JJSs (or adults in corrections³), through their Federal TBI State Partnership Grants (see pp. 7, 11-12). We have also drawn from (3) clinical wisdom (ours and others) regarding screening for and providing services responsive to TBI outside the framework of juvenile justice/ corrections. Both of the first two resources also helped in our **documenting implementation processes**, more specifically, barriers to and supports for planning and carrying out programmatic efforts to address needs of JJS-involved youth with TBI, which are discussed herein.

SUMMARY OF STATE AND FEDERAL POLICY IMPLICATIONS

While Section IV of this guide describes in detail policies at the administrative and state levels, there is **room for discussion at a national level** to assist states in addressing the needs of youths with TBI who encounter the JJS. From our interviews, we found that sustaining and expanding work within states was difficult without resources above and beyond what the state itself was able (or willing) to provide. State resources were clearly limited in both juvenile justice and brain injury systems, with some states having few, if any, TBI-specific resources and services available to them. A first step in bringing awareness to state legislatures is the publication of a brief by the National Conference of State Legislatures which was, as noted earlier, developed as the result of this project (<http://www.ncsl.org/research/civil-and-criminal-justice/traumatic-brain-injuries-report.aspx>).

The conversation regarding TBI among youth in JJSs that needs to take place among federal policy makers and state JJSs should aim at recognizing both the extent of TBI among youths in these systems as well as how this is a problem, not only for these youths but also for

² Another important means of addressing our goal was the development (with the National Conference of State Legislatures) a **document on TBI and JJSs aimed at state legislators and other policy makers**; it is now available online: (<http://www.ncsl.org/research/civil-and-criminal-justice/traumatic-brain-injuries-report.aspx>).

³ We include the adult facilities, as we believe that their experiences may also provide insight into specific supports and barriers encountered when implementing programmatic change in correctional systems in general.

their families and communities – in terms not only of increased recidivism and crime but also of all the costs discussed herein with respect to opportunities lost. This acknowledgement is the first step in garnering resources to help states and local programs in implementing and sustaining their work.

With regard to states, the implications of our findings are that to effectively respond to JJS-involved youth with TBI-related disabilities, **states must:**

- **Make a commitment** to address the needs of youth with TBI in JJSs, specifically the TBI-related challenges that promote poor outcomes, such as increased recidivism and crime;
- Adopt policies and procedures for **screening for and identifying TBI and then assessing identified youths to document TBI-related needs;**
- **Identify resources, both in the community and system-based,** to address the needs of JJS-involved youth who have been identified with TBI-related disabilities, especially cognitive and behavioral issues, from the point of entry into the JJS throughout the period of community re-entry.

The **key areas of challenge** that should be considered at state and local levels include: 1) implementation of new programming, i.e., how to get it done; 2) program elements; 3) administration; 4) program policies; and 5) sustained funding of TBI-adapted JJ services. The specific policy implications with respect to these five areas are detailed in pp. 28-30.

II. BACKGROUND

WHAT IS A TBI?

TBI is an **injury to brain tissue** caused by a blow to the head, such as in an assault, or by rapid acceleration and deceleration, as might happen in a car crash. Such damage leads to **disruption of normal brain function, temporarily or permanently**. To the degree that the injured brain does not completely heal, TBI is associated with permanent impaired functioning – both personal and social. The severity of TBI may range from severe injury to mild TBI (the latter also referred to as concussion). Most moderate and severe injuries are associated with loss of consciousness at time of injury and with relatively poor long-term functional recovery. In contrast, most mild TBIs are associated with relatively rapid and full recovery.

But, **not all mild TBIs are harmless – some have permanent effects**: 1) 15% is a commonly cited figure of those who experience lingering, often major, long-term challenges after a mild TBI (Alexander 1995); and 2) recent research has shown that repeated mild brain injuries (even “sub-concussive” hits) can lead to severe long-term dysfunction, including CTE (chronic traumatic encephalopathy), which has been found, on autopsy, in the brains of boxers and football players, as well as others engaging in contact sports (Omalu et al, 2010; Mez et al, 2017; Alosco et al 2017).

DEFINING THE PROBLEM FOR JUVENILE JUSTICE SYSTEMS

The **consequences of childhood TBI**, even in many so-called mild injuries, can be major – affecting the person’s life, often disastrously. Effects differ for each person, but often a combination of **cognitive** difficulties (e.g., poor memory, reduced processing speed, poor executive functions), **physical** complaints (e.g., headaches, fatigue) and **behavioral** disabilities (e.g., emotional dysregulation, aggression, acting out) emerges.⁴ These changes in the person typically lead to difficulties in functioning in

The Centers for Disease Control and Prevention (CDC) defines TBI as “a disruption in the normal function of the brain that can be caused by a bump, blow, or jolt to the head, or penetrating head injury.”

812,000 children under age of 17, were treated for concussion in 2014.

- Almost half (49%) of TBI-related emergency department (ED) visits by children and youth were caused by falls.
- More than 1 in 4 (28%) TBI-related ED visits in children and youth were caused by being struck by or against an object.
- Falls and motor vehicle crashes were the first and second leading causes of all TBI-related hospitalizations (52% and 20%, respectively).

https://www.cdc.gov/traumaticbraininjury/get_the_facts.html

⁴ How does “TBI” differ from “learning disability”? Or, from a type of learning disability, such as dyslexia? TBI refers to an injury to the brain caused by trauma. The consequences of the injury may include cognitive problems, such as difficulties in learning and in reading (e.g., dyslexia). But these consequences – learning disability and dyslexia – may be commonly found in people without a TBI. And, many people with a TBI do not experience these particular cognitive problems.

social contexts, first within the family and school, and later in adult social relationships and at work. The problems themselves and the reactions of peers, teachers, supervisors and institutions not uncommonly lead to social and societal failure. Consequently, a disproportionately high rate of TBI (relative to the rate in the general population) is found in settings like homeless shelters and vocational rehabilitation facilities, as well as in juvenile justice and adult corrections.

HOW PREVALENT IS TBI IN JUVENILE JUSTICE SYSTEMS?

In our recently conducted systematic reviews of published studies on TBI in JJS-involved youth in the U.S. and elsewhere, in research that spoke to the question of prevalence of TBI, we found no simple answer, but we did find the **average prevalence of TBI to be 44%** across the many studies reviewed (Dijkers & Seger, submitted). Additionally, **TBI was found more often in the JJS-involved youth sample in each study in which they were compared to a similar non-JJS-involved sample**; for the latter, the average prevalence of TBI was 26%. (The 26% prevalence rate in the non-JJS-affiliated samples may seem “high” compared to statistics based on random samples of the U.S. youth population, where typical results suggest prevalence of TBI in children and adolescents in the single digits [Holmes et al., 1991; Silver et al., 2001; Frost et al., 2013; Haarbauer-Krupa et al., 2018]. While many methodological variables may be contributing to the “high” rate among the “non-criminal” youth samples in our review [see Appendix, pp. 42-43], a major reason is that in this case the samples [in each of the several studies included in the systematic review] were typically selected to match the JJS-involved samples on socio-economic variables, such as family income and education level; and, an inverse relationship is typically found between these variables and crime, i.e., lower socioeconomic status is associated with higher rates of TBI and of crime.)

What is TBI’s role in crime? There is no evidence that TBI mechanistically “causes crime”. But we do know that TBI more often precedes rather than follows criminal behavior. For example, in the MS-ICRC’s Texas screening study (Gordon et al., 2017), we found that for youth on parole or incarcerated who screened positive for TBI, the majority (56.5%) reported that their TBI preceded their first offense, rather than followed it. And, as noted in the discussion above, TBI often leads to cognitive, behavioral and emotional challenges that all too often are received with negative and uninformed responses within the youth’s social environment, leading to a vicious cycle of negative reactions leading to aggressive/violent behavior.

The takeaway is that the prevalence of TBI is high in offending youth. And, TBI is associated with earlier, more frequent and more violent crime (Williams et al., 2010, 2018).

TBI SERVICES AND TREATMENTS

Within the U.S. health care and education systems, the extent to which treatment and rehabilitation are provided to children who sustain a TBI with persisting symptoms depends largely on the severity of injury; age at time of injury; availability of resources, including insurance, to pay for extended rehabilitation and services; and the level of expertise within health care and education systems in the affected child’s community. Even children who sustain an injury that leads to hospitalization may not be readily identified by school systems as having sustained a TBI. These children consequently do not receive the specialized educational

services and accommodations that may be needed to address cognitive and behavioral issues triggered by their injury. Instead, they may be provided services/ accommodations that are non-specific to their TBI; they may be inappropriately lumped together with children with other disabilities or health conditions (although TBI is a separate disability category under the Individuals with Disabilities Act [IDEA]).

The CDC reports that about 75% of TBIs are so-called mild injuries (CDC, 2003). However, as noted above, in a significant percentage of mild injuries (the oft-quoted 15%; Alexander, 1995), cognitive, emotional and behavioral problems do emerge immediately and – especially in children – also over time, as the child’s injured brain fails to keep up over the course of his/her development. Children with these less severe, but often still disabling, injuries may never receive any medical attention at all, and their injuries may not be reported to their schools by the child’s parents, who may be unaware of the child’s injury and (especially) its consequences. Others with mild TBI may seek care from emergency departments or from a family physician, who may treat the immediate symptoms and determine if the patient needs to be referred for specialized care, such as to a neurologist or neuropsychologist. Seeking such help does not guarantee that appropriate treatment will be given, as TBI expertise varies greatly across communities and across care providers; although, this may be less true now, with the increased attention being given to sports-related injuries in children and other types of concussion, raising awareness of the need to address the youth’s concussion-related needs.

Typically, whether care is received in a hospital or in outpatient settings, too often the TBI is treated as if it is simply an injury occurring at a single point in time, rather than as the chronic condition triggered by injury that it may become (Masel & DeWitt, 2010). In the former view, once the injury is “over,” the urge is to “move on.” However, too often this means that the person with TBI is under-treated, with challenges triggered by the TBI continuing to act as an undertow in the person’s life. It is like a collective amnesia prevents the person and his/her support network from continuing to see the problem for what it is and, over time, also prevents active monitoring of and addressing TBI-triggered challenges as they emerge.

STATE AND FEDERAL TBI PROGRAMS

Since the 1980s, both the federal and state governments have recognized the growing number of Americans surviving a TBI. Consequently, states have enacted legislation to help prevent brain injuries from happening in the first place or to minimize the aftermath, not only through primary prevention, such as traffic safety laws and prevention efforts aimed at changing personal behaviors (e.g., wearing seat belts), but also via secondary prevention, in the form of improved emergency medical services, trauma care and guidelines for post-concussion care, particularly for school children.

To the degree that these primary and secondary prevention approaches are **un**successful, injuries **do** occur and TBI-related needs emerge, typically affecting the person and his/her social network over a lifetime. To address these on-going needs associated with TBI, **some states have enacted legislation** to dedicate fines or surcharges (largely associated with driving) to pay for services (referred to as trust fund programs); while other state legislatures have appropriated state general revenue. About half of the states administer Medicaid home- and community-based services (HCBS) programs for individuals with TBI; and many states use a

combination of sources to fund services and supports. Kansas, the first state to implement a brain injury Medicaid HCBS waiver program, is now (in 2020) extending HCBS to Medicaid-eligible children and youth with brain injury. Most states have created **advisory boards or councils** to help in assessing TBI-related population needs and in developing state plans to make recommendations for addressing gaps in service delivery, including the need for collaboration and coordination across state agencies and community programs.

State-level TBI programs may be housed in departments of vocational rehabilitation, health, mental health, behavioral health or education; in Medicaid, or in disability-focused private agencies. Services may be spread among many such departments and agencies within a state.

At the federal level, Congress passed the **TBI Act of 1996** – which was reauthorized most recently in 2018. Its purpose is to provide funding to “help states increase access to services and supports for individuals with TBI throughout the lifetime.” The TBI Act requires states to establish an advisory board to conduct planning and coordinate policies. The TBI State Partnership Grant Program (discussed below) was authorized by the TBI Act and initiated in 1997. While the Grant Program is currently housed within the Administration for Community Living (ACL) of the U.S. Department of Health and Human Services, prior to 2016 it operated under the auspices of the U.S. Health Resources and Services Administration (HRSA).

The activities (described below) supported by the **ACL TBI State Partnership Grant Program** comprise a significant portion of efforts aimed at improving identification and services for youth and adults with TBI in U.S. juvenile justice and adult correctional systems. Consequently, these grant-funded activities became of great interest to us in this review of programs/activities that have been tried and the roads taken to achieve successful implementation, as well as the barriers found along the way. Because **the state activities we report on herein were based on four-year grants awarded under this program in 2009 and 2014**, it is important to note that grant guidance issued by HRSA at that time stated that the overall purpose of the federal program was to **address barriers to services** not only for children, youth and adults with TBI but also, for the first time, specifically for those at high risk of TBI, including youth and adults in justice/correctional systems.

A COMPREHENSIVE MODEL OF SCREENING AND SERVICES

Before turning to the model of services that HRSA adopted for grantees to follow, let us consider for a moment a somewhat more comprehensive model. In the best of all worlds, after children experience a brain injury, they would have their needs addressed soon after injury; a brain injury would be viewed not only as needing immediate attention but also as potentially triggering a chronic condition that would need monitoring over time. However, in the real world that we outlined above, most JJS-involved youths with TBI come into the justice system largely with their brain injuries unknown and untreated, with a variety of co-morbidities, such as substance use and attention deficit hyperactivity disorder (ADHD), and often with a history of poverty, mental illness and abuse. How, then, might JJSs respond ideally? And, what evidence is available supporting the effectiveness of programs addressing TBI within JJSs?

Unfortunately, **we cannot turn to published research evidence** of effectiveness in approaching TBI within a JJS context, to support either a model of services or even any single

program or intervention. In our systematic reviews of the literature (Dijkers & Seger, submitted), **we found no studies** published that formally evaluated the impact of programs or treatments that have been tried with youth offenders with TBI. And, it is beyond a researcher's dream that evidence would exist comparing one model to another. Instead, we must rely upon clinical insight and observations of practitioners with long-term experience with TBI and their knowledge of what works – outside the world of JJSs. In the few instances that we have found that JJS programs have been put into place, and that we report on herein, it has been the result of this clinical expertise being put into action and having an impact on policy making, which underlies their becoming funded.

Clinical wisdom suggests two key factors for effective intervention: first, knowing that an individual has a TBI and, second, having a clear understanding of the resulting impairments, or what impairments may develop in the future. That knowledge of functional implications of TBI becomes the basis for teaching the affected youth compensatory strategies for managing challenges such as memory problems, and also to “teach” the social environment how to make accommodations. For example, we can show educational staff that placing a student with a TBI in the front row of the classroom is a possible approach for reducing distraction caused by noise, which is triggered by TBI. Such a model also suggests that we provide similar supports and coordination during the full course of the youth's involvement with the JJS.⁵

We discuss below, and throughout this guide, some examples of programs for identifying youth offenders with TBI and providing appropriate interventions and resources to address cognitive and behavioral problems, within the JJS and after release.

The approach these programs have taken includes any or all of the following:

- **Screening** for TBI, including documenting any persisting symptoms and complaints (self-reported) that followed injury
- **Assessment**, to identify TBI-related problems (e.g., cognitive, behavioral, emotional) at greater depth than in the screening process; based, if warranted and feasible, on a neuropsychological evaluation **by a person with TBI training and expertise**
- **Service planning**, to identify interventions and resources (e.g., education, group therapy, vocational rehabilitation) that fit the individual's needs (based upon results of the assessment and/or in-depth screening)
- Providing **treatments and interventions**, either through JJS staff or through JJS-contracted community providers, aimed at addressing cognitive and behavioral challenges, e.g., learning compensatory strategies
- **Training and educating** JJS staff re: strategies to address cognitive and behavioral problems, including environmental accommodations

⁵ As noted earlier in this document, we cannot pretend that what occurs within the JJS jurisdiction in terms of TBI-related interventions is guaranteed to translate to the social environment that awaits the youth with TBI after discharge. To improve chances that youths with TBI will effectively use the tools they have been taught, we need a strong emphasis on providing transition services, to enable them to translate what they have learned “inside” to the world they face on the “outside.”

- **Resource facilitation or service coordination**, to coordinate resources within the JJS and in the community after the individual is released
- **Monitoring of services provided:** What are the short- and long-term outcomes? How can these data be used to improve services provided?

An example of an approach based on this model, the Brain Injury Linkworker Service, developed by the Disabilities Trust Foundation, was established in England in two “secure” facilities for youth (Chitsabesan et al., 2015). In this program, based on a successful model of interventions developed for adult offenders, the linkworker/coordinator was incorporated into a service structure similar to what is bulleted above. (Note: Although Chitsabesan et al. describe the program, they do not evaluate its costs and successes relative to ‘usual care’.)

An important set of elements in this more comprehensive model ensures that training/ education is provided to juvenile justice staff, service providers and family (when appropriate), to ensure that accommodations, interventions and strategies for addressing behavioral and cognitive problems are consistent across settings: facility, home and community. While this “wraparound approach”⁶ by and large has not been adopted in the TBI field, the philosophy behind it lends itself well to youth with TBI. “Wraparound” embraces a planning process that involves the individual, family (when appropriate/possible) and natural supports, as well as community and educational services; these elements work together to support the individual in the community over time.

In the mental health system, the wraparound process is related to the system-of-care framework, comprising a coordinated network, which builds meaningful partnerships with families and youth, and addresses their cultural and other needs, with the aim of helping them to function better at home, in school, in the community and throughout life.⁷ For example, the Child and Adolescent Service System Program (CASSP) uses a coordinated network of mental health and other support services to meet the evolving needs of children and adolescents with severe emotional problems. (A link to a description of how CASSP has been implemented in Pennsylvania is provided in Section V, p. 33.)

THE HRSA “BARRIERS TO SERVICES” MODEL

The HRSA Model, refers to the U.S. Health Resources and Services Administration (HRSA), which in 2014, awarded the federal TBI grants to the states and as such, determined priorities for funding. The HRSA model stems from the body of research showing that a large number of youth in JJSs have an unidentified TBI that affects their cognitive and behavioral functioning, thus impacting their judgment, awareness and ability to function and live in JJS institutions and programs and, subsequently, in society. By identifying these individuals, the model suggests

⁶ The wraparound approach, used most commonly with children and youth with serious mental health or behavioral challenges, has proved to be successful in keeping children in their communities by being able to respond to crises and provide supports within the home and community in lieu of institutionalization. It requires collaboration and coordination of agencies to work together to support the individual’s immediate and long-term needs and goals. It recognizes that children and families often interface with multiple systems with different purposes, such as child welfare, mental health, substance use, education and primary health care – all systems that may also interface with JJS-involved children and youth with TBI.

⁷ National Technical Assistance Center for Children’s Mental Health
https://gucchd.georgetown.edu/products/Toolkit_SOC_Resource1.pdf

that one could then provide strategies and accommodations for addressing cognitive and behavioral deficits as well as coordination of services, reducing the likelihood of the person's returning to the juvenile/criminal justice system. However, missing from this model is treatment focused on TBI-based impairments, due in part to the relatively small amount of funds to which HRSA had access and the relatively high cost of providing individual and even group treatments. HRSA determined that four types of supports were needed to respond to the four sets of common barriers and were feasible within resource limitations:

| Barriers to Services | Supports Needed |
|---|---|
| (1) Lack of TBI diagnosis or incorrect diagnosis | Screening |
| (2) Lack of information about services and supports | Information and referral (I&R) services |
| (3) Lack of trained health and other professionals to provide needed services | Professional training |
| (4) Difficulty in identifying and navigating multiple service systems and agencies upon discharge | Resource facilitation |

Within the HRSA model, these components were to be implemented at the various points that youths encounter the JJS: Initial contact with law enforcement, intake (whether into a detention center or probation and parole) and at time of release. After youths are taken into custody, they would go through an intake process conducted by intake officers, probation staff, case and social workers or police. At intake, states would integrate TBI screening questions or tools into existing intake procedures, with the goal of determining lifetime history of TBI. Once identified, individuals "positive for TBI" would be referred for further evaluation/assessment, which might be conducted by the psychologist in the JJ setting or by a neuropsychologist, who might be under contract through the grant or the TBI state program.

The purpose of assessment was to identify TBI-related disabilities and suggest methods/strategies for addressing symptoms. State TBI programs would provide information and referral (I&R) services, which would be charged with identifying resources and services that might be available to the person with TBI. Then the youth would be assisted in obtaining those resources, via resource facilitation or service coordination.

Both I&R services and resource facilitation were to be provided either by the state TBI program or through contract with another appropriate entity. Training would be provided either in discrete training sessions or offered continually, e.g., through web-based curricular offerings or as a part of the routine juvenile justice staff training. Training would focus on understanding: 1) screening procedures; 2) the utility of screening; 3) TBI-related symptoms, impairments and behavior problems; and 4) methods for addressing behavioral and cognitive disabilities related to TBI.

STATE FEDERAL TBI GRANTEES FOCUSING ON JJ/CORRECTIONS: OVERVIEW

In 2009, four of the HRSA Federal TBI state grant recipients (MN, NE, TX, VA) targeted youth and/or adults in criminal justice systems in their grant activities; in 2014, seven states (AL, CO, IA, IN, ME, MO, PA) participated; herein these 11 states are referred to as “past grantees”. After the program was transferred to the ACL, two states (CO, PA) currently continue using grant and other funds for work in juvenile/criminal justice; they are referred to herein as “current grantees.” (One of the 2009 state grants supported the Texas project mentioned above that focused on screening for TBI in the JJS, in which MS-ICRC staff trained Texas JJS personnel at both the state and county levels to screen for TBI.) Again, we are grateful to all past and current grantees for their willingness to share their implementation experiences with us, as well as provide us feedback on a draft of this resource guide.

An important point in understanding the context in which the state grants were and are being implemented is that JJSs differ greatly from state to state. And, within the states, county and municipal procedures and facilities (if any) may differ greatly from those the state itself establishes. However, statewide JJ agencies provide some degree of system oversight in all states. This variation led to challenges. For example, past grantees involved in county systems reported in their interviews with us that counties varied with regard to their participation in grant activities and in resources to do so. Some grantees consequently chose to sample a limited number of sites, for example, a rural and urban site, to pilot their program.

Within this context and given other circumstances that we discuss below, none of the state TBI grantees were able to implement the HRSA model in full. Further, state grantees piloted their activities either in one component of the overall system, such as a detention center, or probation and parole, or only in certain counties willing to participate. These grant activities were carried out in county jails (2 states), with probation and parole/juvenile probation officers (3 states), state JJ agencies/facilities (4 states), adult correctional facilities or community-reentry/diversion entities (6 states), with a few states covering more than one area.

Grantees approached their mandate with impressive variation. For example, some states worked with attorneys and judges involved in problem-solving courts and drug courts. While many of those who were interviewed discussed screening, training and resource facilitation being provided (and described how these program elements were provided), much less was reported in terms of implementation of treatments, accommodations and strategies addressing TBI-related disabilities within JJSs. Information & referral services and resource facilitation were either carried out by the state TBI program – some of which have such capacity – or through contracts with the state affiliate of the Brain Injury Association of America (BIAA) or of the U.S. Brain Injury Alliance (USBIA), as well as other providers, using funds from the HRSA grant.

Implementing the HRSA Model: Lessons Learned:

- **Degree of success was strongly associated with the degree to which the department of corrections/juvenile justice was integral to the planning of grant activities, and the degree to which buy-in was achieved.**
- States **were more successful when integrating screening questions** into the existing intake interview process, which, then, was more likely to continue after the grant funding ended.
- Successful state grantees **were more likely to already have in place prior to grant funding I&R services and TBI resource facilitation or service coordination within their state TBI programs**, rather than depending on grant funding to support these activities.
- States had less capacity for addressing or arranging for assessment, treatments or accommodations for TBI-related symptoms. This could have been due to the short time-frame to implement activities under the grant.
- One state used a self-reported symptoms questionnaire as an intermediate step prior to assessment, based on the realization that a full-scale evaluation was not always needed nor feasible with every youth with a lifetime history of TBI.
- Once grant funding ended, grant activities were at risk for ending, unless the **JJS incorporated such activities within their policies and administrative functions.**

III. STEPS FOR ADDRESSING TBI IN JUVENILE JUSTICE SYSTEMS

DEVELOPING THE PROGRAM FRAMEWORK AND BUILDING SUPPORT *(Deciding What You Want to Do, and How to Get It Done)*

Introduction

In deciding what they wanted to do and how to go about it, grantees uniformly found that **ongoing leadership, commitment and support among multiple agencies were key in creating a plan and structure that led to successful implementation**. Work groups or task forces were seen as necessary for planning and overseeing program implementation. However, such planning operations do not come without a price. It does take staff time and resources to get the work done. While federal grant funds may be available to support the preliminary work, e.g., planning, piloting, if there are no further grant opportunities available, then identifying other means to fund such activities is paramount. And, that typically will involve getting state policy-makers and/or legislators involved, to the degree that state-level policy change and/or funding are needed. The following are steps and considerations to consider in pursuing this JJS-focused work.

Laying the Groundwork: Awareness and Education

If the concept is new to state policymakers, then **conducting awareness activities and education** regarding TBI prevalence and TBI-related disabilities among youth offenders is a logical first step in the process. Additionally, raising awareness should focus on the fact that **juveniles with TBI can learn ways to better live with their disabilities**: by learning to use external supports, such as a daily or weekly diary, which helps accommodate memory challenges; by learning ways to better problem solve, a skill set that can be ravaged by TBI; and learning techniques for regulating emotional functioning rather than acting out aggressively. This type of learning can be introduced within JJSs. The goal is not only to improve youths' behavior while JJ-involved but also in their subsequent functioning, when they are back in their community on parole and after. The point could be made that, **if you want to reduce recidivism (AKA reduce crime)**, target a group that commits more crime, and more violent crime: youth with TBI. Perhaps legislators and other policy makers are open to the possibility of investing in a programmatic approach to crime reduction – at relatively low costs with a strong potential payoff, in the form of fewer violent crimes.

Advisory councils or boards (e.g., the state TBI advisory council or board, the state juvenile justice advisory council) may be vehicles to start the discussion. These councils may arrange for speakers on the topic during their meetings, convene task forces to gather information and to lay the foundation, and/or sponsor or co-sponsor statewide conferences featuring speakers on this topic. Another avenue may be to request state lawmakers to convene an ad-hoc committee to study the issue and raise awareness. These are just a few suggestions of ways to inform and educate those who are in leadership and administrative positions to help them understand the

correlation of TBI with juvenile offending, the relationship with crime and how the state may be able to address these issues to ensure successful community integration.

In the states in which we conducted interviews, **the impetus for taking programmatic action on TBI and youth/adult offenders varied greatly.** Obviously, when the federal agency administering the TBI State Grant Program identified juvenile offenders as a priority population, some states chose that focus in order to receive funding. This often occurred because a staff member, for example, in the state's Department of Health, was particularly interested in the intersection of TBI and justice/corrections. In one state, a state legislator wanted to know the prevalence of TBI in the JJ population, and the TBI State Partnership Grant Program provided a convenient mechanism to get an answer. In another state, it was about "timing": a TBI advisory board member was interested in how many people in the criminal justice setting have brain injuries, which coincided with a university professor offering her students the opportunity to conduct neuropsychological screening in a county jail as a practicum. In another state, the TBI program had received a grant from the corrections department, and after a successful pilot with adults, they decided to expand to include youth.

States cited as an impetus the work of other states, as well as the research showing the high prevalence of TBI in juvenile justice and adult criminal justice systems. One state convened a policy summit inviting other states to share their experiences, resulting in a summit document. Another state has convened two meetings of personnel within states that were engaged in TBI programs to share their progress in implementation. (See Section V, pp. 31-32, for reports on these meetings.)

Identifying Leadership

Leadership is key in beginning the process of implementing change, whether in the form of screening, treatment and/or accommodations to address TBI-related disabilities. To implement these activities within a JJS takes planning, resources, authority to change policies, and access to key partners and collaborators essential in carrying out the activities. In some states, this leadership came from the state agency administering TBI services, while in others, the leadership came from the juvenile and criminal justice systems themselves. The work can be initiated by a Governor's executive order, by an advisory council or board (state brain injury advisory board and/or state juvenile justice council), by brain injury and/or social justice advocates, or by the head of a state agency interested in pursuing a programmatic approach.

The process may require one or more officials with policy-making authority who can affect committees that are responsible for administrative duties of the JJ facility or program involved in serving youth offenders, as well as TBI programs and professionals to assist with training, treatment and coordination of resources.

Regardless of who convenes a committee or task force, identifying who should be part of the process is key. Individuals and organizations to consider include:

- √ **State TBI programs**
- √ **State affiliate of BIAA or USBIA**
- √ **State and county juvenile justice systems**
- √ **State Department of Education and/or local school districts**

- √ **State Department of Mental Health, Substance Abuse (behavioral health)**
- √ **Professionals with TBI and/or mental health expertise**
- √ **Social justice organizations**
- √ **Individuals/groups invested in improving the JJS**
- √ **County juvenile justice programs (e.g., probation and parole)**
- √ **Specialized courts, such as family, drug, mental health and problem-solving courts**
- √ **Child health, protection and welfare representative(s)**
- √ **State vocational rehabilitation agency**
- √ **Developmental disabilities councils**

Identifying key stakeholders can make a difference in whether needed activities can be implemented at all, and if so, will be successful. When putting together a task force to plan and implement the activities, these are some questions to ask in considering people to invite:

- *Can the person speak on behalf of the agency or organization?*
- *Can the person dedicate his/her own time or staff time to help plan the activities?*
- *Can the person grant access into the JJ program, setting or system?*
- *Can the person require staff to be trained?*
- *Can the person commit to developing screening policies and other policies that may be necessary?*
- *Can the person commit resources necessary to carry out the activities on an on-going basis – whether within the state’s TBI program or juvenile justice/ correctional system?*
- *Can the person help in gaining support from the governor and/or state legislature, to ensure that funding or necessary legislation is obtained and/or that the program continues?*
- *Can the person be a spokesperson for the project by presenting at juvenile/criminal justice conferences or other educational opportunities?*
- *Can the person help in developing and implementing evaluation measures and collecting data to assess outcomes?*
- *Can the person represent agencies such as vocational rehabilitation, education, Medicaid, mental health and alcohol and substance abuse, to bring resources beyond the JJS to the table?*
- *Can the person represent the interests of JJ advocacy associations or organizations involved in improving JJSs?*

There may be other key movers and shakers in the state who may be able to help advance the work, such as state lawmakers, attorneys, judges and organizations focused on disabilities other than TBI.

Planning and Implementation

A committee or task force may direct the work and identify steps to be taken to begin the project. Questions for the committee to consider include:

- ***Should the program start as a pilot project in one area of the state or statewide? In which setting(s), e.g., state detention centers, probation and parole, county-level programs? At what points in the JJS's jurisdiction over the youth?***

States interviewed piloted their projects, choosing: 1) an area of the state to target, 2) a facility, 3) a county program or 4) the probation and parole program. Some states chose an urban setting and a rural setting to begin their work. This was often determined by the willingness (or lack thereof) of the state JJ program to participate. Some states chose to implement screening early in the youth's involvement and others later; an example of the latter was at initiation of probation. In some instances, after initial "small" efforts, the project expanded to include other similar programs and/or other partners, such as judges and attorneys. In some states that have county-based systems, it meant that each county program had to be approached and engaged separately; whereas, with a statewide JJ program, a single agency could make the needed commitment.

- ***Who can help secure needed resources to develop and implement the program?***

Are there resources available through grants or existing programs? Is there interest in pursuing new funding sources to support the initial and ongoing work? If the state administers a TBI program, that program may be able to identify professionals to assist with developing and evaluating screening approaches as well as with training staff to conduct screening, treatment, accommodations and referral to resources. Also, a State Brain Injury Association or State Brain Injury Alliance and/or rehabilitation programs in the state, if any, may help with locating experts and sources for training and providing materials.

- ***How can support be obtained from JJS administrators and staff?***

States that were successful in implementation of their programs engaged JJS program administrators and staff **early on and fully involved them in the planning process**. They were key to making the program work and offered ways to incorporate staff training and screening of involved youth into their existing intake policies. In one state, the TBI state program is in the same state agency as the JJ agency and already had a relationship due to previous training of staff in that division. In two other states, the departments of corrections and juvenile justice had developed a collaborative relationship through previous grant funding. In yet another state, the corrections department and the state coalition against domestic violence had a history of collaboration through a federal Violence Against Women Act (VAWA) grant to identify incarcerated women and survivors of domestic violence, who as a result, may have sustained a TBI. In another case, the state TBI program and the state mental health agency, which had an existing relationship, together provided supports to the JJ agency.

Amongst the state grantees, the degree to which successful relationships were established with and support obtained from their JJSs varied greatly. States encountered unforeseen barriers, such as legal counsel or sheriffs who viewed screening as creating legal liability. One of the 2009 grantees that was unable to succeed early in the grant period, due to reorganization within the corrections system and turnover of staff within its own agency, told us that interest was resurrected later, largely due to support/intervention from groups involved with intellectual/

developmental disabilities. These organizations reached out to the TBI advisory council and the Brain Injury Alliance affiliate to partner in developing a report on juvenile justice and disabilities to forward to the governor. (Clearly, in these examples, not everyone who should have been at the planning table had been.)

In sum: Leadership support is critical both in initially developing policies and in obtaining resources for programmatic changes.

Developing the Program Framework and Building Support: Lessons Learned

Laying groundwork is key.

1. Identifying and getting buy-in from key players may be quite complex within states having systems that are more localized, being carried out at the community level, with different players from region to region or county to county.
2. Support and leadership may come from unexpected places – in one state, it was the university that expressed interest and played a key role in assisting with screening and assessment.
3. Laying groundwork and establishing relationships take time
4. One current grantee created an advisory team comprised of representatives from each target site and from partners, as well as subject matter experts in brain injury; it meets quarterly to monitor ongoing activities. The advisory team has also conducted focus groups with all the target sites and clinicians assisting with screening.
5. Another state partners with the Juvenile Court Judge’s Commission, the Juvenile Detention Center Association and various providers in the community who work with juvenile offenders.

The TBI state program’s understanding of JJSs in the state is also key.

1. Some states added representatives from the juvenile justice/correctional systems to their state TBI advisory council to help with such understanding and how to engage support.
2. Conversely, there may be opportunities for juvenile justice staff, agencies and organizations to better understand TBI and state TBI resources and programs through state conferences, task forces and other venues.
3. **High rates of staff turnover in state systems, state budget shortages, changing priorities for state agencies and other factors may impede progress in implementing and sustaining activities.**

TBI Resources (see also Section V, pp. 31-33)

With regard to capacity and availability of services for individuals with TBI, considerable differences exist across states and within a state. On the “better” end, states offer service

coordination/case management and an array of community rehabilitation services and supports, as well as operate a TBI advisory board or council. However, some states provide none-to-few of the services and supports available in “richer” venues.

In terms of informational resources, a wide array of information on TBI is available through the TBI Model Systems program, funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), specifically through the Model Systems Knowledge Translation Center (www.msctc.org/tbi). The National Association of State Head Injury Administrators also maintains information on state TBI services and resources (www.nashia.org). Additional online resources are available through brainline.org, biausa.org and usbia.org.

PROGRAMMATIC ELEMENTS (*The Specifics of “What You Want to Do”*)

Screening for TBI

Overview of Screening

Screening and assessment are two different procedures. Screening is generally a brief interview using structured questions to document a self-reported history of TBI; while an assessment is conducted after a positive screen to confirm the history of TBI(s) and determine the nature and severity of cognitive, behavioral and emotional disabilities due to TBI. To help guide the selection of the screening tool and deciding when a youth is to be screened, these questions should be asked:

- *Is the purpose to help determine the prevalence of TBI within the JJS, meaning lifetime history of TBI?*
- *Is the purpose to determine who has a probable TBI with persisting symptoms and problems that get in the way of the youth’s achieving good outcomes?*
- *Is the purpose to determine who has a probable TBI and needs further assessment of TBI-related symptoms, prior to providing appropriate treatment and/or accommodations?*

While some states simply added screening questions (of their own device) to their current battery of intake questions, most used a formal screening tool for identifying TBI. Several either used or adapted the Ohio State University Traumatic Brain Injury Identification Method (OSU TBI-ID), the HELPS screening tool or the Brain Injury Screening Questionnaire (BISQ). (See Resources in Section V for links to these screening tools.)

In selecting methods for screening, these are important considerations:

- *Will information be available from the youth’s past medical, school or other records?*
- *Will information be obtained by self-reporting and/or will it require participation and/or authorization by parents or guardians?*
- *At what point will screening be done? Will this maximize the feasibility of implementing assessments/interventions, to achieve good outcomes?*
- *Through what mechanisms will the results of screening be communicated throughout the youth’s encounter with different components of the JJS?*
- *What type of expertise is needed by staff to conduct screening?*
- *Will staff training need to be provided, and will it be required in JJS policies?*

- *How much time will be needed to conduct the screening?*
- *What are the costs involved with regard to the screening tools and accompanying documentation?*

Who conducts the initial screening?

In some states, the juvenile justice/corrections staff may conduct the screening, while other options include juvenile probation officers or family court mental health case managers. Within detention centers, intake procedures may be implemented by the nursing staff, psychologist and/or social workers. In a few states, the grant funded contract staff from a community TBI provider to conduct screening. Other state JJSs are considering integrating TBI screening into their other existing screening processes. A concern expressed by some states focused on the requirements or credentials necessary for the person who is administering the screening tool or who is asking the required questions; either these states do not have qualified personnel and/or training of personnel is problematic, e.g., staff turnover adds to training demands.

When does screening take place?

Almost all states employed screening at the time of intake or admission to a detention center. One state added TBI screening questions as part of the process at the state's reception diagnostic center, where every youth entering the JJS is put through a medical, dental, psychological and educational evaluation. Another state had intended to screen all offenders being discharged back into the community, regardless of the offense; but due to staff shortages and turnover, it switched to reviewing medical records to screen those offenders that had reported a medical/mental health issue in their records. Another TBI state grantee conducted screening at the time of parole and work release; those youths with the likelihood of having a TBI were referred for resource facilitation, to help with supports needed for community reintegration.

Who receives screening information?

(The cautions described below also apply to assessment information – see pp. 20-22.)

Administrators may need to develop policies with regard to who receives the information resulting from screening. In general, screening information is intended to be used by staff and those who are involved with youth in the JJS. But, should parents receive the information, especially if they have been involved in situations of abuse? While health-related information is protected by confidentiality laws, those who are involved in legal proceedings may request the information to use it in the adjudication process, which may not be an appropriate use of the information.

In one state program, a two-page report for the jail or probation staff is generated; it outlines the test results, as well as some simple recommendations that staff can use to support the youth. They also give a feedback sheet to the inmate or probationer, providing a summary of test results in lay language (“It looks like you have some short-term memory loss. Here are some things you can do to address that.”). It doesn't ‘prescribe’ any specific treatment, but focuses more on accommodations and supports. If youths screen positive for serious neuropsychological impairment, they are referred to the Brain Injury Alliance affiliate for case management.

Screening: Lessons Learned:

- Some states found that administrators/staff needed to obtain approval from parents/guardians to conduct screening and/or assessments,
- Some parents refused screening or could not be located. In some instances, the parent had committed child abuse and was not viewed as appropriate for answering questions.
- Youth being screened often did not want to self-report – admitting TBI may be seen as admitting weakness.
- Parents and those being screened often reported different information.
- A concern expressed in some states is with over-reporting. Youth or family may report something that involves the head being struck, but the child does not exhibit TBI-related symptoms.

Examples:

- **Probation and Parole.** In states in which probation and parole staff already assessed juveniles to determine who is at-risk due to mental health or substance use, with the initiation of the grant they added additional screening questions to ascertain if a TBI might be a comorbid condition and a contributor to the problems that a juvenile is exhibiting. Some state grantees, after a positive screen, offered the opportunity for further evaluation and assessment to determine need for treatment, accommodations and strategies to address cognitive and behavior-related deficits, as well as suggestions for coordinating with education, vocational or other programs that the juvenile may need in addressing TBI-related issues.
- **Youth Detention Facilities.** One state relies on screening conducted by the medical/mental health providers that conduct intake at the detention facility operated by the state agency. Another state contracted for staff associated with the state TBI program to conduct screenings and is working with the nursing staff from the program to provide services in the state's youth detention centers, in order to integrate brain injury screening into current procedures.

Assessment

Overview

Once a youth screens positive for TBI, he or she should ideally be referred for a neuropsychological assessment. A neuropsychologist is a Ph.D.-level psychologist specializing in knowledge of brain function (especially that of the injured brain). The purpose of the referral is to get a better understanding of the youth's cognitive and behavioral deficits and their implications for accommodations and services that may be needed. Neuropsychologist consultants review screening results and other materials available, e.g., medical history; they also administer

neuropsychological tests. Based on these multiple sources of information on the person's history and current functioning, they make recommendations to address the youth's TBI-related challenges.

One state conducted a follow-up phone call to the youth after screening, but before referring for further assessment, to determine if referral for a formal assessment was needed. This state, as well as one other, used interview questions and assessments recommended by their TBI state program.

The capacity for offering an assessment varied across the states. Some built into their grant's budget funds to pay for a neuropsychologist or psychologist to conduct the assessment. One state provided assessments in two ways: 1) student clinicians from the university conducted a neuropsychological assessment, or 2) for those in a state juvenile justice facility, the state agency conducted the assessment using an on-site psychologist. In another instance, an advisory board member who is a neuropsychologist volunteered, along with two neuropsychology interns, to conduct neurocognitive testing. In one state, after the youth was referred for case management/resource facilitation, the state USBIA association, under contract with the TBI state program, implemented the Mayo Portland Assessment Inventory (see Section V).

Once their grant funding ended, some states proposed that community mental health coordinators or psychiatric hospitals be considered for conducting the neuropsychological assessment, with funding from the state TBI program or through Medicaid.

Who receives assessment information?

Depending where the youth is in the system (e.g., courts, detention center, probation and parole), information from the assessment may be shared with:

- Juvenile justice staff involved in case planning and management,
- The youth and family (the latter, only if appropriate), with regard to strengths and weaknesses,
- The service coordinator/resource facilitator, who may be involved in planning for community services and supports.

Detention center staff may communicate with the youth's juvenile probation officer to educate him/her about memory and other cognitive issues that may impede the youth from making appointments or other commitments without some type of assistance, such as written reminders.

States did note that the family was not always appropriate to receive the information. Sometime abuse has taken place. States also noted legal concerns as identifying a TBI-related disability does not mean causation of the offense.

Assessment: Lessons Learned

- Most JJSs do not employ a neuropsychologist or have capacity for conducting a neuropsychological assessment.
- The system may have an on-site psychologist who could be trained to conduct such an assessment; the quality of an assessment depends to a large extent on the assessor's TBI expertise.
- Prior to referral for a full-scale neuropsychological evaluation, administering a symptoms questionnaire or a screen for impairment may be a more affordable approach. The former, full-scale, evaluation is clearly needed if the youth continues to struggle after accommodations have been implemented based on symptoms reported.
- State TBI programs may be able to help with the costs; Medicaid may also be a source for reimbursement.
- An issue arises as to the amount of time a juvenile may be involved with the justice system: if the youth is involved for only a short "stay", then the time span from screening, through assessment, to developing appropriate accommodations and strategies for addressing issues and concerns identified may be relatively short.

Training

Overview

Approaches to training varied across states. Some grantees integrated training into their existing staff training curriculum, while others made online training available in staff break rooms, having uploaded curricular materials onto their website for ease of access.

In keeping with grant requirements, states offered training to those targeted in their grants, ranging from first-responding police officers and sheriffs/deputies to JJS staff (e.g., psychologists, counselors, medical personnel), court staff, probation and parole officers, youth services agencies/organizations and youth advocates. Some states took a blanket approach, i.e., making training available to all staff across the state involved in the state's criminal justice system. One state also trained health care staff in the community. Another state trained staff of the TBI service program with which it was cooperating, to have non-JJS personnel better understand the JJS's processes and partners.

Training topics included basic understanding of TBI (e.g., causes, symptoms), interventions and accommodations, as well as substance use.

A group that was not targeted to receive training included parents, guardians and caretakers of juveniles within JJS jurisdiction, although in ideal conditions such training would receive high priority.

Most states focused on training with regard to screening. Some paid for training conducted by John Corrigan, Ph.D., the psychologist who led the development of the Ohio State University Traumatic Brain Injury Identification Method (see p. 32).

How is training provided?

States provided training on-site and/or online, via webinars, during conference workshops or with a combination of these methods. Some states relied on the training (online) that the Minnesota Department of Corrections has developed. Training was provided by state lead agencies⁸, state associations of the BIAA or USBIA, or by other experts in the state. Some states worked with their juvenile/criminal justice systems to incorporate TBI training into the training curricula of JJS staff, defining what is provided to or required of staff.

Training: Lessons Learned:

- Staff turnover and/or lack of time for training juvenile/criminal justice staff, particularly those working in detention centers, tend to be problematic.
- Juvenile justice residential programs have multiple shifts involving different staff in a 24-hour day. Because of the nature of their work responsibilities, training is often hard to schedule.

Interventions and Accommodations for TBI-related Disabilities

The purpose of assessment is to evaluate cognitive and behavioral deficits to gain insight into needed and feasible methods of addressing the youth's challenges in daily life functioning. As an example, individuals with anger issues may need a group treatment program or counseling that is designed to take into account the youth's associated cognitive problems. Thus, a counselor knowledgeable about TBI knows that if the counselee has memory problems, repetition will be a key to success; the counselor does not assume that "saying something once" is sufficient or that youths' insight into their behavior will always carry over from one session to the next.

States did not seem to target their grant resources to address challenges associated with TBI, except for training staff on general accommodations for TBI-related problems such as anger. In other words, grant funds were not primarily used to pay for cognitive rehabilitation or other treatment, or for professional services to help with identified deficits. This was due in some cases to the short length of time juveniles were in these systems, as well as lack of professionals with TBI expertise. In general, treatment and attention to disability issues tended to be viewed as being provided in-house, at least in juvenile detention centers. However, if the youth were on probation and parole while in school, then the responsibility would be seen as resting with the school district. States that contracted with TBI providers were primarily the ones that aided youths with TBI-related accommodations, strategies and services, such as counseling.

⁸ The state agency with primary responsibility for planning, coordinating, and providing TBI services and supports.

What interventions, strategies and accommodations are available to JJSs in addressing problems of youths with TBI? First, **nothing can be done without first identifying TBI** through screening – if you don't know a youth has a TBI, any interventions provided will likely be ineffective because of cognitive challenges that get in the way of a youth's benefitting from the service, such as in the example above. But, identification in and of itself only indicates the size of the problem, i.e., prevalence of TBI. To address the needs of youth with TBI, we suggest that **the next step**, after identification, is **assessment by a neuropsychologist well-versed in TBI**.⁹ This professional can suggest specific directions to take in addressing the youth's specific needs. If this is infeasible because of costs or unavailability of expertise, use of a needs assessment, e.g., that developed by Heinemann et al. is suggested. (See Section V, p. 33)

Interventions may include **individual therapy**¹⁰ (by a neuropsychologist, psychologist, counselor or social worker with expertise in TBI), which may help the youth manage behaviors or learn coping strategies, as well as providing counseling as needed for better emotional and psychological well-being. These interventions ideally would take a cognitive-behavioral approach to treatment, with cognitive remediation embedded. A **speech-language therapist** may also be beneficial to assist with cognitive function and communication skills. An **educator trained in TBI** may be useful in helping JJS staff to help offenders with TBI to organize their day and to carry out tasks expected of them. These professionals may be part of the JJS or available under contract.

Other interventions include **group treatments that target cognitive and emotional challenges faced by youth with TBI**, such as STEP and Y-STEP (see pp. 1-2 and Section V, p. 33), which are led by trained professionals; these were developed and evaluated by the MS-ICRC, with CDC funding, as well as prior support from NIDILRR. STEP and Y-STEP (the latter is the STEP intervention adapted for use with youth) are targeted at post-TBI executive dysfunction (e.g., bad decision making, inability to plan ahead) and emotional dysregulation (e.g., acting out, aggressiveness). An additional group program developed by the MS-ICRC can be administered online, with the professional running the group in one location and the group members clustered in a second place, e.g., a detention center. The latter group treatment focuses solely on improving emotional regulation and so is referred to as EmReg. Because it is a web-based group treatment, EmReg provides access to TBI-knowledgeable professionals, who would be otherwise unavailable, particularly for people living in rural areas of the United States (Tsaousides et al., 2014).

As to environmental **accommodations**, JJS personnel – from top to bottom – can receive training on how to shape their own actions and behaviors to support youth offenders with TBI, to help them better follow JJS demands on them while under JJS jurisdiction and to achieve better long-term outcomes, through teaching them compensatory strategies and skills.

⁹ It should be emphasized that an assessment by a neuropsychologist is only recommended if he/she has experience with and expertise in TBI. If that is an infeasible option, assessment by a psychologist, particularly a rehabilitation psychologist with training in TBI is recommended. As noted above, a fallback if funds are scarce, is training staff to administer systematic assessments, such as those referenced in Section V herein.

¹⁰ These would ideally be a cognitive-behavioral type of treatment with embedded cognitive remediation.

Youth in residential or short-term facilities receive educational services, and as such, those with TBI-related disability may be eligible for **special education** and related services provided under the IDEA. They may, as well, be afforded rights under the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act and under applicable state laws. The 1990 Amendments to IDEA added TBI to the category of disabilities eligible for special education and related services, provided other requirements are met. In accordance with IDEA, juvenile justice facilities must have policies in place with regard to Child Find, to identify youth with a disability. Screening and assessment as discussed in this guide will help identify youth with TBI-related symptoms, which may qualify the individual as eligible for special education and related service, even though he or she may not have been identified previously in a public-school setting. Screening and assessment will also help to determine accommodations needed for academic learning that can be put in place through a Section 504 Plan, should the person not qualify under IDEA. (Section 504's definition of disability is broader than under IDEA.)¹¹

A formalized assessment of cognitive and academic skills will help to form an individualized education plan (IEP) in accordance with IDEA, which is a written statement of the educational program designed to meet a child's individual needs or a Section 504 plan, noting accommodations needed to attain academic success. Youth determined eligible for special education services under IDEA must meet all three of the following criteria:

- The student must have a disability or disabilities.
- The student's disability/disabilities adversely affect educational performance.
- The student's unique needs cannot be addressed through education in general education classes alone – with or without individual accommodations and requires specially designed instruction.

A few state TBI programs have partnered with their state education agency to develop educator training and consultative services to assist with developing IEPs and educational strategies. Resources are available in the appendices.

Clearly, what needs to be addressed in initial planning of programmatic changes in JJSs is the need for **expanded resources** (i.e., funding) for such individual and group treatments being implemented as early in the period of JJS involvement as possible, while the offender is under relatively greater control and before TBI-related challenges build upon themselves. Interventions should not be put off to the point of community re-entry, where less control is held by the JJS and **where opportunity may be lost** to prevent the snowballing of TBI-related problems.

Community Re-entry/Integration: Information & Referral; and Coordination of Resources

Once a youth has been identified as having sustained a TBI with relatively permanent and substantial impairments and is being released, community assistance may be available to help coordinate access to needed services and supports. State TBI programs accessed their TBI service coordinators/resource facilitators, or contracted with state associations of the BIAA or USBIA or with other TBI service providers. The challenge is to access information on TBI and to

¹¹ Under 504, a student must be determined to have a physical or mental impairment that substantially limits one or more major life activities, have a record of such an impairment or be regarded as having an impairment.

coordinate resources. Or if the youth is on probation or parole, the challenge is to help advocate for accommodations in the school setting.

If youth are referred for TBI resource facilitation/service coordination, then the resource facilitator may follow up with the youth, by phone or in person, to assess continuing and newly emerging needs and to develop a plan to address those needs. Resource facilitation may include an intake process, assessment, service planning, coordination of resources, follow-up, family/client education and monitoring of services. The process may address needs for medical care, employment preparation and job training, and/or education.

In two states, the state TBI program began to involve Medicaid, as these states had brain injury home- and community-based waiver programs (for adults) and discovered that some of the Medicaid staff had experience with mental health and correctional issues. In most communities, several resources were available to assist with helping youths return to school or get a job, a good starting point being the state vocational rehabilitation agency.

Community Re-entry: Lessons Learned

- In many states, assistance with community re-entry depended on HRSA federal TBI grant funding, *even in those states that already had state-funded TBI services.*
- In one state, the grantee was concerned about the additional number of individuals that would be added to its service coordinators' caseload.
- **Community re-entry services and supports largely depend on what is already available in the state.** Specialized TBI services and supports are not readily available in all states; however, resources that are available in all states, include vocational rehabilitation, mental health, Medicaid and transition services.

FINANCIAL RESOURCES

Overview

Funding is always a key issue for states, particularly if additional funds are needed – beyond the existing state budget for JJ and TBI programs – to pay for assessment, treatment and other relatively costly services. Some state JJSs may have state funding to pay for medical care that could be used for specialized TBI assessment, treatment and behavioral/cognitive rehabilitation or access Medicaid for health care for delinquent youth in the custody of the JJS.

Medicaid

Youth who are not incarcerated may be eligible for therapies and treatment under the state Medicaid program. Under Medicaid, beneficiaries up to age 21 (and former foster children up to age 26) receive early and periodic screening, diagnostic and treatment (EPSDT) services. The purpose of EPSDT is to ensure that children and youth receive appropriate preventive, dental, mental health, developmental and other specialty services. Under EPSDT, states are required

to provide comprehensive services and furnish all Medicaid-coverable, appropriate and medically necessary services to correct and ameliorate health conditions, based on certain federal guidelines.

About half of the states administer Medicaid TBI home- and community-based services (HCBS) waiver programs; all states administer intellectual/developmental disabilities waiver programs; and some administer children's waiver programs. These waivers generally specify an age requirement, which varies across states. Most of the TBI HCBS programs offer counseling and therapies, such as behavioral and cognitive therapy, for individuals who are eligible.

State Revenue/Trust Fund

About half of the states administer a state TBI program through the state's general fund and/or dedicated funding from traffic-related fines, primarily, known as trust fund programs. Some of the programs either contract or provide service coordination or resource facilitation services. A state advisory board or council is often associated with the program to provide oversight and/or planning for service delivery.

Vocational Rehabilitation

State VR agencies often pay for neuropsychological assessment to determine level of functioning, as the basis for offering job training and placement.

DATA AND PROGRAM EVALUATION

Most states interviewed found that collecting data with regard to successful community re-entry over the long term was challenging for a number of reasons. In some states, the juvenile justice programs are spread among counties and community programs that may have jurisdiction for those services, so that data collection and processing capabilities may differ among the entities. Also, some youth are in the system for such a short time that they are difficult to track. Finally, data may not be shared from one agency to another. For example, youth referred to state TBI programs may be assessed for progress by the program, but that information may not be shared with the JJS.

Although not potentially as helpful as outcome data, documentation of program activities may be useful in gauging the impact of training, screening and the like. Thus, most states interviewed conducted pre- and post-testing with regard to staff training. In one state, an advisory group continues to meet after grant implementation ended, to monitor and evaluate the activities still being conducted. This group also holds focus groups (with staff), to receive input to improve methods for identification and provision of services and resources.

IV. SUMMARY AND POLICY IMPLICATIONS

OVERVIEW OF IMPLICATIONS AT THE STATE LEVEL

The policy implications below are based on three sources: the interviews the MS-ICRC conducted with ACL TBI state grantees (see pp. 7, 11-12), expert clinical opinion, and results of a systematic review of the literature on the intersection of juvenile justice and TBI, conducted by the MS-ICRC.

In general, at the state level, to effectively identify and respond to JJS-involved youth with TBI-related disabilities, states must:

- Make a commitment to address youth with TBI in JJSs, specifically the TBI-related challenges that promote poor outcomes, such as increased recidivism and crime;
- Adopt policies and procedures for screening for and identifying TBI;
- Identify resources to address the special needs of youth who have been identified with TBI-related disabilities, especially cognitive and behavioral issues; and,
- Identify community resources that can provide youth and family the supports they need throughout the period of community re-entry.

The key areas for recommended changes that should be considered at state and local levels include: 1) implementation of new programming, 2) program elements, 3) administration, 4) program policies and 5) sustained funding of TBI-adapted JJ services.

IMPLEMENTATION OF NEW PROGRAMMING

- **All agencies** involved with providing services and developing policies with respect to JJS-involved youth **must be at the planning table** in order to obtain commitments to support both new programming, e.g., screening, assessment and interventions, as well as training staff in providing appropriate cognitive/behavioral accommodations. In addition to personnel from corrections and TBI programs, this should include representatives from education, vocational rehabilitation, job training, substance abuse and mental health agencies, as appropriate. All those who make decisions potentially affecting programming, administration and funding should be participants in program planning from the get-go.
- This planning group, with its diverse partners, should continue involvement as a council/committee charged with **monitoring progress**.

PROGRAM ELEMENTS

- Offending youth need to be identified via **TBI screening**, preferably at admission to the JJS.
- **Assessment** of individuals who screen positive for TBI should be conducted by qualified professionals, with the focus on assessing the extent and nature of cognitive and behavioral problems, and defining functional implications and needed interventions, behavioral strategies and accommodations. In the best of worlds, this would be a neuropsychologist with extensive TBI experience.

- **TBI training** is aimed at assuring that all levels of staff involved with offending youth (e.g., detention, prison, probation, parole, judges, lawyers) are made aware of the many challenges associated with TBI and the accommodations that they can make.
- When possible and appropriate, parents or guardians as well as offending youth should be provided with **TBI education**.
- **TBI interventions** need to be provided to offending youth while they are in the system, starting at the earliest point possible. Without planning to provide interventions, why screen or assess?
- **All interventions provided them should be modified for individuals with TBI.** For example, cognitive behavioral therapy (to treat clinical depression) has been successfully modified to address TBI-related challenges, such as poor memory and concentration (Ashman et al., 2014).
- **Resource facilitation** and **service coordination** are necessary and useful in linking individuals to community-based TBI services and resources.

ADMINISTRATION

- The capacity to **evaluate outcomes** in the short- and long-term needs to be ensured. Efforts should be made to develop consistency in measuring outcomes across settings and jurisdictions, so that comparisons can be made across venues (local, statewide, national), to get a better picture not only of the extent of TBI (prevalence), but also (and more importantly, since we already have a clear picture of high prevalence [see p. 5]), the impact of TBI on youth in JJSs and the effects of introducing program changes.
- **Integrating screening and training into existing frameworks** is key, not only in terms of the **design of the innovations but also the methods used in introducing innovations and assuring their continuation in the program.** This needs to be considered in terms of existing screening or **in-take processes, training curricula** and **methods for sustaining innovations**, especially in consideration of staff turnover within systems, multiple agencies being involved and the relatively short period that some youth are involved in JJ systems.
- **Advocating for resources and supports** to enable JJ staff and agencies to engage in these activities is key.

PROGRAM POLICIES

Program policies should be put in place with regard to the following:

- Who should receive information in accord with **confidentiality requirements**, recognizing there may be instances where family may have been involved in abusing the child and that attorneys may want information for purposes other than to ensure that they provide appropriate assistance within the JJS.
- Who within the JJS and who without (e.g., families) has **access to screening and assessment outcomes**.
- **Referrals and agreements** with community-based TBI providers, rehabilitation professionals and TBI programs that can help, as needed, with assessment, treatment, counseling, developing accommodations and strategies, and the like.

FUNDING

- **Sustaining the program** requires continued commitment by state and community agencies/staff and policymakers (also see below).

* * *

Beyond these policy implications aimed at states and what they might be doing differently with respect to JJS-involved youth with TBI, as noted at the outset of this resource guide, **policy implications at a national level** are clearly implied within all three sources of ‘data’ that we have drawn upon, but especially in the reports of the ACL. Consequently, **the conversation regarding TBI in juvenile justice-involved youth needs to take place amongst federal policy makers and state JJSs**, with the aim of recognizing the extent of TBI amongst youths in these systems and also recognizing how this is a problem, not only for these youths, but also for their families and communities – in terms not only of increased recidivism and crime but also of all the costs discussed herein with respect to opportunities lost. This acknowledgement is the first step in garnering resources to help states and local programs in implementing and sustaining their work.

V. Resources

GENERAL INFORMATION ON TBI

- National brain injury associations in the U.S.
 - Brain Injury Association of America (www.BIAUSA.org)
 - United States Brain Injury Association (www.USBIA.org)
- Model System Knowledge Translation Center on TBI (<https://msktc.org/tbi/model-system-centers>): Wide-ranging information and resources on traumatic brain injury, including fact sheets, slide shows, info-comics, videos, “hot topics”, research database, systematic reviews and info on TBI Model Systems
- Brainline.org (www.brainline.org) Information on TBI for people with TBI, caregivers, professionals, military and veterans, and children with TBI
- National Center for Injury Prevention and Control, CDC (www.cdc.gov/ncipc/tbi/TBI.htm) Information for professionals and others interested in TBI, on prevention, causes, outcomes and research; available for downloading: data reports on TBI, publications, fact sheets. Materials are available in English and Spanish

GENERAL INFORMATION ON TBI AND CRIMINAL/JUVENILE JUSTICE

- CDC overview of TBI in prisons and jails:
https://www.cdc.gov/traumaticbraininjury/pdf/Prisoner_TBI_Prof-a.pdf
- Publication: Traumatic Brain Injury and Juvenile Offending: Complex Causal Links Offer Multiple Targets to Reduce Crime (Williams et al, JHTR, 2015:
https://www.nursingcenter.com/journalarticle?Article_ID=2767394&Journal_ID=515677&Issue_ID=2767393
- Webinar/presentation: Bridwell A & MacDonald R. Traumatic brain injury in the criminal justice population. Council of State Governments Justice Center, New York, NY, February 11, 2014. <https://csgjusticecenter.org/wp-content/uploads/2014/02/TBI-Slides-2.11.14.pdf>
- Brief overview of the need for interventions for youth with TBI in JJSs:
<https://jjie.org/2017/06/26/untreated-traumatic-brain-injury-keep-youth-in-juvenile-justice-system/>
- Overview of problem, British perspective and approach:
<https://www.internationalbrain.org/youth-offending-and-abi-a-practical-approach/>

ACTIVITIES OF TBI STATE PARTNERSHIP GRANTEES (CRIMINAL/JUVENILE JUSTICE)

- **Overviews**
 - State Approaches for Addressing Traumatic Brain Injury within the Juvenile Justice System; includes overviews of Pennsylvania, Colorado, Minnesota and Virginia programs (written for legislators by the National Council of State Legislatures in conjunction with MS-ICRC, via CDC funding):

http://www.ncsl.org/Portals/1/Documents/cj/Traumatic-Brain-Injuries-Juvenile-Justice_v02_web.pdf

- Report on experiences of TBI State Program grantees in a meeting convened by the Alabama grantee, 2017: <https://www.du.edu/tbi/media/documents/cj-jj-summit-report.pdf>; similar report in 2016: <http://www.alabamatbi.org/uploads/1/3/8/3/13834569/al-jj-report-recommendations-final-pictures.pdf>
- Report on Virginia Collaborative Policy Summit, meeting of 5 state grantees, 2013: <https://www.vadars.org › cbs › downloads › VirginiaCollaborativePolicySu...>

- **Pennsylvania**

- Webinar/presentation: Piccolino, A. TBI in Corrections: Beyond the Screening Process. Presentation at the NASHIA State of the States Conference. 2012. <http://www.nashia.org/pdf/sos2012/pres-piccolino-2012-sos-presentation.pdf>
- Publication: Piccolino, A.P., & Solberg (2014). The Impact of traumatic brain injury on prison health services and offender management. *Journal of Correctional Healthcare*, 20 (3), 203-212. <https://www.ncbi.nlm.nih.gov/pubmed/?term=piccolino+a>
- Brief overview of Pennsylvania project: http://www.paproviders.org/archives/secure/Children/TBI_Grant_Summary.pdf
- 2017 conference slides, overview of brain injury, as well as the PA program: <https://www.jcjc.pa.gov/Program-Areas/AnnualConference/Documents/2017%20Conf%20Docs/Brain%20Injury%20in%20Youth%20Offenders%20%20A%20Hidden%20Disability.pdf>

- **Colorado**

- University of Denver's perspective on Colorado's program on Traumatic Brain Injury in Criminal Justice: <https://www.du.edu/tbi/index.html>
- A Manual for Educators on Brain Injury in Children and Youth, developed by the Colorado Department of Education; basic information about TBI in children, from a developmental perspective: http://www.cde.state.co.us/cdesped/tbi_manual_braininjury
- Report on Colorado's program, 2015: <https://portfolio.du.edu › downloadItem>

- **Minnesota**

- Article on identification of youth with TBI in JJSs, from Sharyl Helgeson, Minnesota Department of Human Services; <https://www.brainline.org/article/identifying-brain-injury-state-juvenile-justice-corrections-and-homeless-populations>

PROGRAM COMPONENTS: SCREENING

- Brain Injury Screening Questionnaire (BISQ): Contact: wayne.gordon@mountsinai.org; use of the BISQ in screening for TBI in Texas JJS, ACRM abstract: [https://www.archives-pmr.org/article/S0003-9993\(16\)30527-5/pdf](https://www.archives-pmr.org/article/S0003-9993(16)30527-5/pdf)
- Ohio State University Traumatic Brain Injury Identification Method (OSU TBI ID): <https://wexnermedical.osu.edu/neurological-institute/departments-and-centers/research-centers/ohio-valley-center-for-brain-injury-prevention-and-rehabilitation/osu-tbi-id>
- HELPS TBI Screening Tool: <https://www.nashia.org/pdf/hotopics/pa-helps-screening-tool.pdf>

PROGRAM COMPONENTS: NEEDS DEFINITION, ASSESSMENT, TREATMENT

- Publication: Heinemann AW et al. Measuring unmet needs and services among persons with traumatic brain injury. Arch Phys Med Rehabil. 2002 Aug;83(8);1052-1059.
<http://www.ncbi.nlm.nih.gov/pubmed/12161825>
- Publication/Guidelines: Interview for Community-based Assessment of Needs (I-CAN): contact wayne.gordon@mountsinai.org
- Mayo-Portland Adaptability Survey: <http://www.tbims.org/combi/mpai/>
- Training videos, technical assistance: Short-term Executive Plus (STEP), contact: birc@mountsinai.org

CHILDREN AND ADOLESCENTS SERVICE SYSTEM PROGRAM (CASSP)

- Description of CASSP in Pennsylvania
http://www.dhs.pa.gov/cs/groups/webcontent/documents/document/c_260462.pdf

EDUCATION

- Colorado Kids with Brain Injury: <https://cokidswithbraininjury.com/>
- Brain Injury in Children & Youth: A Manual for Educators, Colorado Department of Education: http://www.cde.state.co.us/cdesped/tbi_manual_braininjury
- National Association of State Special Education Teachers, <https://www.naset.org/index.php?id=traumaticbraininj2>
- TBI Tips and Academic Accommodations, Center for Brain Injury Research and Training, <https://www.crporegon.org/cms/lib/OR01928264/Centricity/Domain/50/Academic%20Accommodations%20CBIRT.pdf>
- Transition Toolkit 3.0: Meeting the Educational Needs of Youth Exposed to the Juvenile Justice System, Third Edition, December 2016, developed by the National Technical Assistance Center for the Education of Neglected or Delinquent Children and Youth
<http://www2.ed.gov/students/prep/juvenile-justice-transition/transition-toolkit-3.pdf>

VI. Appendices

REFERENCES

- Alexander MP. Mild traumatic brain injury: pathophysiology, natural history, and clinical management. *Neurol.* 1995;45:1253-1260.
- Alosco ML, Mez J, Tripodis Y, Kiernan PT, et al. Age of first exposure to American football and long-term neuropsychiatric and cognitive outcomes. *Transl Psychiatry.* 2017 Sep 19; 7(9); e1236.
- American Congress of Rehabilitation Medicine. Definition of mild traumatic brain injury. *J Head Trauma Rehabil.* 1993;8(3):86-87.
- Ashman T, Cantor JB, Tsaousides T, Spielman L, Gordon W. Comparison of cognitive behavioral therapy and supportive psychotherapy for the treatment of depression following traumatic brain injury: a randomized controlled trial. *J Head Trauma Rehabil.* 2014 Nov-Dec;29(6):467-78.
- Brown M, Dijkers M, Gordon W. Interview for Community-based Assessment of Needs (I-CAN). New York: Department of Rehabilitation and Human Performance, Icahn School of Medicine at Mount Sinai; 2019.
- Centers for Disease Control and Prevention. Report to Congress on mild traumatic brain injury in the United States: Steps to prevent a serious public health problem. CDC: National Center for Injury Prevention and Control, 2003.
- Chitsabesan P, Lennox C, Williams H, Tariq O, Shaw J. Traumatic brain injury in juvenile offenders: Findings from the Comprehensive Health Assessment Tool Study and the development of a specialist linkworker service. *J Head Trauma Rehabil.* 2015;30:106-115.
- Dijkers M, Seger M. TBI in juvenile justice populations: prevalence and comparison with peers. Submitted for publication.
- Frost RB, Farrer TJ, Primosch M, Hedges DW. Prevalence of traumatic brain injury in the general adult population: a meta-analysis. *Neuroepidem.* 2013;40(3):154-9.
- Gordon WA, Spielman LA, Hahn-Ketter A, Sy KTL. The relationship between traumatic brain injury and criminality in juvenile offenders. *J Head Trauma Rehabil.* 2017;32(6):393-403
- Haarbauer-Krupa J, Lee AH, Bitsko RH, Zhang X, Kresnow-Sedacca MJ. Prevalence of parent-reported traumatic brain injury in children and associated health conditions. *JAMA Pediatr.* 2018 Nov 1;172(11); 1078-1086.
- Holmes CB, Buzzanga VL. Head-injury prevalence among community college students. *Perceptual and Motor Skills.* 1991;73(2):497-498.
- Hux K, Bond V, Skinner S, Belau D, Sanger D. Parental report of occurrences and consequences of traumatic brain injury among delinquent and non-delinquent youth. *Brain Inj.* 1998;12(8):667-681.

Lewis DO, Yeager CA, Blake P, Bard B, Strenzoik M. Ethics questions raised by the neuropsychiatric, neuropsychological, educational, developmental, and family characteristics of 18 juveniles awaiting execution in Texas. *J Am Acad Psychiatry Law*. 2004;32(4), 408–429.

Masel BE, DeWitt DS. Traumatic brain injury: a disease process, not an event. *J Neurotrauma*. 2010;27:1529-40.

Mez J, Daneshvar DH, Kiernan PT, Abdolmohammadi B, et al. Clinicopathological evaluation of chronic traumatic encephalopathy in players of American football. *JAMA*. 2017 Jul 25;318(4):360-370.

Omalu BI, Hamilton RL, Kamboh MI, DeKosky ST, Bailes J. Chronic traumatic encephalopathy (CTE) in a National Football League player: Case report and emerging medicolegal practice questions. *J Forensic Nurs*. 2010 Spring;6(1):40-46.

Silver JM, Kramer R, Greenwald S, Weissman M. The association between head injuries and psychiatric disorders: findings from the New Haven NIMH Epidemiologic Catchment Area Study. *Brain injury*. 2001;15(11):935-945.

Tsaousides T, D'Antonio E, Varbanova V, Spielman L. Delivering group treatment via videoconference to individuals with traumatic brain injury: A feasibility study. *Neuropsychol Rehabil*. 2014;24(5):784-803.

Williams WH, Chitsabesan P, Fazel S, McMillan T, Hughes N, Parsonage M, Tonks J. Traumatic brain injury: a potential cause of violent crime? *Lancet Psychiatry*. 2018;5(10), 836-844.

Williams WH, Cordan G, Mewse AJ, Tonks J, Burgess CNW. Self-reported traumatic brain injury in male young offenders: A risk factor for re-offending, poor mental health and violence? *Neuropsychol Rehabil*. 2010;20(6), 801-812.

ACRONYMS AND ABBREVIATIONS

ABI – Acquired brain injury

ACL – U.S. Administration for Community Living

ACRM – American Congress of Rehabilitation Medicine

AL – Alabama

ADHD – Attention deficit and hyperactivity disorder

BIAA – Brain Injury Association of America

BISQ – Brain Injury Screening Questionnaire

CASSP – Child and Adolescent Service System Program

CDC – Centers for Disease Control and Prevention

CO – Colorado

CTE – Chronic traumatic encephalopathy

DHHS – Department of Health and Human Services

EPSDT – Early and periodic screening, diagnostic and treatment services

HCBS – Home and community-based services

HRSA – U.S. Health Resources and Services Administration

IA – Iowa

IDEA – Individuals with Disabilities Education Act
I&R – Information and referral
IN -- Indiana
JJS – Juvenile justice system
JPO – Juvenile probation officer
MN – Minnesota
MS-ICRC -- Mount Sinai Injury Control Research Center
MSKTC – Model Systems Knowledge Translation Center
NASHIA – National Association of State Head Injury Administrators
NE – Nebraska
NIDILRR – National Institute on Disability, Independent Living and Rehabilitation Research
OSU TBI-ID – Ohio State University TBI Identification
P&A – Protection and advocacy systems (i.e., disability rights)
TBI – Traumatic brain injury
TX – Texas
USBIA – U.S. Brain Injury Alliance
USDHHS – U.S. Department of Health and Human Services
VA – Virginia
VR – Vocational Rehabilitation
WBLE – Work-based learning experiences

DEFINITIONS AND TERMINOLOGY

Juvenile Justice-Related Terminology

(Source: National Juvenile Offender Center: <http://njdc.info/juvenile-court-terminology/>)

Adjudication – Refers to a formal finding by the juvenile court that the juvenile has committed that for which he or she is charged.

After Care – After care, or “parole”, refers to supervision of a juvenile who has been returned to the community on conditional release following a commitment or incarceration. The youth must comply with certain conditions of release and is monitored by a caseworker or parole officer. Parole can be revoked if the youth does not comply with conditions.

Arraignment -- A portion of the “initial hearing,” interchangeable with the term “presentment,” in which the youth is brought to court and read the formal charges against him or her that are alleged in the petition. This is when a juvenile must admit or deny the charges. Court-appointed or private counsel for the juvenile must be present at this proceeding.

Commitment or Placement or Incarceration – This is one of the options available to the court as a possible sentence. It is the transfer of legal responsibility over the child to the state and often includes placement in a private or state-run facility. In many jurisdictions the court will impose an indeterminate sentence upon transferring custody of the respondent to a state agency, allowing the agency to determine when the youth may be released from incarceration based on good behavior, noted rehabilitation, and the youth’s prior juvenile record. A youth may also be subject to commitment as a sanction resulting from a probation revocation hearing.

Commitment occurs only after adjudication, as opposed to “detention,” where a youth may be placed pending an adjudicatory or disposition hearing.

Deferred Adjudication -- This refers to when a judge decides not to adjudicate the youth and instead impose conditions that, if met, will result in dismissal of the charges. A variation on this is when the court decides to grant a “stay of adjudication,” which suspends the adjudication in situations where the court determines that the circumstances of the case warrant the child being given a “second chance.” If the child satisfies all conditions set forth by the court, the court can dismiss the charge and there will be no record of the adjudication.

Detention -- Juveniles charged with delinquent acts may be detained by court order pending an adjudicatory and/or disposition hearing. A youth may be placed in a detention center at different points throughout the juvenile case. At times, an adjudicated juvenile may be held in detention during a period of their commitment. There are different levels of detention for juveniles. “Secure detention” involves holding the child at a locked detention facility. “Shelter homes,” sometimes referred to as “non-secure detention,” are also a level of detention where the child may only leave the premises for school or other pre-approved appointments. “Home detention,” where the child may only leave home for school or appointments, is an option in some jurisdictions. In jurisdictions where there is no juvenile detention facility, children may be detained pre-trial in adult facilities.

Detention Hearing -- A hearing in which the judge decides whether to detain the child pending an adjudicatory hearing in a delinquency matter. Most jurisdictions require a detention hearing to be held within forty-eight (48) to seventy-two (72) hours after the detention commences to determine whether continued detention is necessary. There must be a finding of probable cause that the child committed the alleged delinquent act before pre-adjudicatory detention is permitted. If probable cause is found, in most jurisdictions there must also be a showing that the child is a flight risk or that the child is a danger to his or herself or others such that continued detention is required pending an adjudicatory hearing.

Disposition -- Disposition refers to a final decision as to how a juvenile’s case is handled after an adjudication. Juvenile courts expressly focus on rehabilitating children who are adjudicated as delinquent and typically include a treatment plan to address perceived deficiencies in the child’s current living environment and behavior. To determine an appropriate disposition, the judge should consider evidence about the juvenile’s needs, available resources, and other relevant factors so as to design a plan to meet the juvenile’s rehabilitation and the interests of the state. Disposition outcomes vary and may include but are not limited to, fines, restitution, community service, in-home placement under supervision or probation, and out-of-home placement in commitment facilities.

Disposition Hearing -- This hearing is held after a juvenile has been adjudicated. At the hearing, the judge decides the appropriate sanctions and treatment for an adjudicated juvenile after hearing recommendations from the prosecution, probation staff, the defense, the child’s parents and/or other potential stakeholders. After considering the disposition plans and recommendations, the judge will give the court’s official disposition order, (e.g., probation, commitment, community-based sanctions, etc.).

Disposition Order – This is a written, signed document handed down by the court that states the disposition chosen for the youth and any conditions of that disposition.

Disposition Plan/Report -- In preparation for a disposition hearing, various stakeholders will prepare plans or reports outlining the care and types of rehabilitative services the party believes the child needs as a result of the adjudication. These proposed plans are most typically prepared by the probation department and the defense, while other stakeholders, such as the prosecution or services provides, may also provide reports or recommendations. In preparation of anticipated plans, the court may order psychological evaluations, diagnostic tests, or a period of confinement in a diagnostic facility to aid in the determination of an appropriate disposition. *See also* Disposition; Disposition Hearing; Disposition Order.

Diversion -- Refers to any program that is an alternative to the filing of a court petition and which keeps the youth from entering the juvenile court system by referring the child to counseling or other social services. Diversion is designed to enable youth to avoid a formal charge through the filing of a petition, which could result in adverse collateral consequences and, ultimately, a juvenile delinquency record. By completing the requirements of a diversion program run by the police department, court, prosecution's office, or an outside agency, the youth can avoid prosecution. While true diversion programs are those that divert the child from any formal charge in the juvenile system, many practitioners and jurisdictions use the term diversion to include programs that are initiated after the client is petitioned, but which result in a non-adjudicatory resolution and the eventual dismissal of the petition. Informal adjustment is a form of diversion.

Guardian *ad litem* (GAL) -- An attorney or advocate appointed by a court to represent the best interests of a child in court proceedings, including juvenile delinquency cases. The role of GAL is different from defense counsel's role to represent the expressed interest of the child in delinquency cases.

Initial Hearing -- This is the first hearing a child accused of a delinquent act will have in front of a judge. The structure of this hearing varies by jurisdiction, but typically includes assignment of counsel, arraignment, a detention determination, and the scheduling of further hearing dates.

Intake -- The screening and assessment process children who are arrested undergo prior to seeing a judge. Intake procedures vary between jurisdictions, but are typically conducted by intake officers, probation staff, case and social workers, or police. At the intake screening, each youth is evaluated to determine his or her appropriateness for release or referral to a diversionary program, or whether the matter should be referred for prosecution.

Petition -- The charging document filed in juvenile court by the state. The petition formally initiates a juvenile proceeding alleging that a juvenile is delinquent and describing the alleged offenses committed by that child. The petition may ask that the court assume jurisdiction over the juvenile or ask that the juvenile be transferred to criminal court for prosecution as an adult. It is similar to a complaint in adult court. *See also* Complaint.

Post-disposition -- Post-disposition refers to the period following the court's entry of a disposition order and lasting until the youth is no longer under the supervision of the juvenile court or any state agency to which he or she was transferred as a result of a commitment.

During post-disposition, a variety of procedures or hearings regarding the client can require the assistance of counsel. These include, but are not limited to, conducting an appeal or helping the client obtain new appellate counsel; representing the youth in probation and parole violation hearings, at commitment review hearings, or at extension of incarceration hearings; challenging condition of confinement that violate the client's state and constitutional rights or circumvent services ordered by the court; and any other legal counseling required until the youth is no longer supervised in the case.

Pre-disposition Report -- Sometimes called a "social history" or "social study," it is a report to the court, prepared by probation staff, that outlines the child's background and recommends a disposition plan. It is a compilation of information on the circumstances of the current offense, the youth's past offense(s), family history, educational progress, and community involvement. Based on these factors, the agency will often make recommendations for disposition.

Probation -- A disposition option available to the court as an alternative to commitment, in which an adjudicated juvenile may be released back into the community under certain conditions and under the supervision of a probation officer for a specified period of time.

Probation Officer -- An employee of the probation department who works closely with the court and is involved with a juvenile's case at various stages of the proceedings. Preliminarily, a probation officer may perform the initial intake interview to determine if a case can be diverted from the juvenile court. Subsequently, if a petition is filed, a probation officer may be responsible for supervising juveniles not held in detention. Probation officers often prepare a predisposition report for the court after a child has been adjudicated and make recommendations for disposition. If a juvenile is placed on probation at disposition, the probation officer provides supervision of the juvenile.

Revocation Hearings/Violation Hearings -- A review hearing at which the state or supervisory agency is alleging that the juvenile has not fulfilled his or her conditions of parole, probation, or pre-trial release. If the court revokes the child's parole, probation, or pre-trial release, it may move the juvenile to some form of out-of-home placement.

Risk Assessment Instrument -- A tool used to assess a youth's likelihood (or risk) of future re-offending. Items on these instruments can reflect both life circumstances (e.g. history of child abuse) and personal characteristics (e.g. attitudes and past behaviors) that have been found to predict future problem behavior. Within the context of the juvenile justice system, risk assessment instruments can be used at different decision-making points (e.g. diversion, detention, or disposition). The briefer screening instruments, such as those often used to determine whether or not to detain a youth, generally consider more basic characteristics that are unchanging, such as the current alleged offense or prior arrest history. More comprehensive risk assessment instruments generally consider a broader range of risk factors, and can be used to guide treatment planning.

Social History -- A collection of records regarding the juvenile's familial, occupational, educational, and community background—the various aspects of the juvenile's life that may be relevant to an evaluation of the juvenile and to determine the appropriate level of services needed. In some jurisdictions, social history is a general term for any collection of such records,

while in others, it is the term used for a pre-disposition report compiled by probation.

Status Offense -- An offense that would not be a crime if it were committed by an adult. Examples of these non-criminal offenses that are only applicable to children include: truancy, curfew violations, running away from home, incorrigibility, and ungovernability.

Transfer/Waiver of Jurisdiction -- The legal procedure for determining whether the juvenile court will retain jurisdiction over a juvenile case or whether the matter will be sent to adult criminal court. A reverse waiver occurs where a child is originally charged in adult court, but is sent back to juvenile court for trial or disposition.

TBI- and Service-Related Terminology (State and Federal)

Advisory board/council – States have established advisory boards or councils to be responsible for planning and coordinating policies, services and resources for individuals with TBI and their families. These bodies may be established by way of a governor’s executive order or state law. They are generally composed of individuals with TBI, families, service providers, professionals and representatives of various state programs, such as vocational rehabilitation, education, health, injury prevention and behavioral health. The federal TBI Act of 1996, as amended, requires states to have an advisory board as a condition to receive federal grant funds.

Cognitive disability –This refers to a number of conditions, including traumatic brain injury, that impact the process of acquiring knowledge, learning and understanding. A person with a cognitive disability by definition has challenges in one or more of the following aspects of cognition: thinking, reasoning, problem solving, information processing, awareness and memory.

Executive Functioning –This term is sometimes used interchangeably with “higher-level cognitive skills.” Both refer to skills and mental processes that enable a person to initiate, plan, focus attention, remember instructions and handle multiple tasks simultaneously.

Home and Community-based Services (HCBS) – HCBS encompasses an array of health and human services in the home and community in lieu of institutional care. HCBS are usually associated with Medicaid programs, which funds HCBS for long-term services and supports in lieu of institutional and nursing level care for individuals who are eligible for Medicaid. These services may include therapies, counseling, in-home support, personal care and transportation.

Lead agency – This term was coined by the U.S. Health Resources and Services Administration (HRSA) to refer to a state agency designated by the state’s governor to be responsible for planning and assuming primary administrative responsibilities for individuals with TBI and their families. ACL TBI state grantees are required to identify a state agency as the lead agency in the state for TBI.

Model Systems Knowledge Translation Center – This Center is funded by NIDILRR. It provides a variety of publications and other resources based on published research relating to TBI; and it houses a variety of materials and resources developed by the 16 NIDILRR-funded TBI model system centers. <https://msktc.org/about>

National Institute on Disability, Independent Learning and Rehabilitation Research

(NIDILRR) is a federal agency that funds disability-related research. It came into existence in 1978 within the U.S. Department of Education, as the result of Title II of the Rehabilitation Act of 1973. The agency is currently housed in the Administration for Community Living (ACL) of the U.S. Department of Health and Human Services.

Neuropsychologist – This is a psychologist who specializes in understanding the relationship between the physical brain and behavior. Some neuropsychologists (not most) have been trained and have clinical experience in applying specialized knowledge in the assessment, diagnosis, treatment and rehabilitation of individuals with TBI.

TBI Model Systems – NIDILRR funds 16 model system centers to provide coordinated systems of rehabilitation care and conduct research on recovery and long-term outcomes post TBI. In addition, these centers serve as platforms for collaborative, multi-site research, including research on interventions using randomized controlled trials (RCTs).

TBI State Program – This refers to an identified state government program that is charged with planning and/or providing or contracting for services and supports for individuals with TBI and their families. The program may be funded with state (general revenue) appropriations, funds derived from a designated funding account, generally referred to as a trust fund, Medicaid or a combination of these sources.

Trust Fund Program -- Trust funds are accounts established by state law and earmarked for specific purposes, such as prevention, services, resources and prevention. Funds are generally derived from traffic-related offenses, although some states may assess fines associated with boating while intoxicated (BWI), surcharges to driver's licenses or allow donations to contribute to the fund. The funding in these accounts generally is carried over fiscal years in order to continue accumulation of funds. Often, the law establishing the fund will also establish a board or council to oversee the fund.

Work-based Learning Experiences -- Work-based learning experiences is an educational approach or instructional methodology that uses the workplace or real work to provide students with the knowledge and skills that will help them connect school experiences to real-life work activities and future career opportunities. This may include in-school or after school opportunities, experiences outside of the traditional school setting, and/or internships.

NATIONAL/STATE ASSOCIATIONS

- Alabama Head Injury Foundation (not affiliated with BIAA or USBIA): <http://www.ahif.org/>
- Brain Injury Association of America: <https://www.biausa.org/>
- Coalition for Juvenile Justice: <http://www.juvjustice.org/>
- Council of Juvenile Correctional Administrators: <http://cjca.net/>
- National Association of State Head Injury Administrators: <http://www.nashia.org/>
- National Conference of State Legislatures (NCSL): <http://www.ncsl.org/>
- National Disability Rights Network: <http://www.ndrn.org/index.php>
- U.S. Brain Injury Alliance: <http://usbia.org/>

FEDERAL AGENCIES

- **U.S. Department of Health and Human Services:** <https://www.hhs.gov>
- **Centers for Disease Control and Prevention**, National Center for Injury Prevention and Control: <https://www.cdc.gov/injury/index.html>
- **U.S. Administration for Community Living (ACL)** TBI State Partnership Grant Program

The Administration for Community Living was created around the fundamental principle that older adults and people with disabilities of all ages should be able to live where they choose, with the people they choose, and with the ability to participate fully in their communities.

Website: <https://www.acl.gov/>. It's programs include:

- Assistive Technology Programs: <https://www.acl.gov/index.php/programs/assistive-technology/assistive-technology>
 - Centers for Independent Living: <https://www.acl.gov/node/410>
 - National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR): <https://www.acl.gov/node/606>
 - State Protection & Advocacy Systems for TBI: <https://www.acl.gov/node/70>
 - Traumatic Brain Injury (TBI) State Partnership Grant Program: <https://www.acl.gov/node/461>
- **Office of Juvenile Justice and Delinquency Prevention:** <https://www.ojjdp.gov/>

Through formula and discretionary grants, cooperative agreements, and payment programs, the Office of Juvenile Justice and Delinquency Prevention (OJJDP) specifically supports awardee efforts to develop and implement effective and coordinated prevention and intervention programs and to improve the juvenile justice system so that it protects public safety, holds justice-involved youth appropriately accountable, and provides treatment and rehabilitative services tailored to the needs of juveniles and their families. OJJDP provides funding to states, territories, localities, tribal communities and private organizations. The formula and block grants are available to states and territories through the state agency designated by the governor.

The Juvenile Justice and Delinquency Prevention Act (JJDP) established State Advisory Groups; SAG members are appointed by Governors/Chief Executives in each U.S. jurisdiction. They are principally responsible for monitoring and supporting their state's progress in addressing the core requirements of the JJDP.

PREVALENCE OF TBI WITHIN JJSs: METHODOLOGICAL ISSUES

There is no "simple answer" to the question of how prevalent TBI is in JJSs, primarily because several factors influence the prevalence of TBI across studies that try to provide "an" answer:

- **How TBI is defined:** For example, a researcher who defines TBI as "being dazed and confused or unconscious consequent to a blow to the head" will find more study participants who say "yes, I've had a TBI" than if the definition only includes a person experiencing unconsciousness. Similarly, if prevalence is defined in terms of the number of people who have experienced blows to the head with immediate symptoms, but disregards whether the post-traumatic symptoms persisted or not, the prevalence rate will be higher than if a TBI is counted only if it triggers lasting functional complaints and symptoms.

- **How screening is conducted by the researchers:** For example, a screening questionnaire designed for brevity (e.g., using a single question to screen for TBI: “Have you ever experienced a traumatic brain injury? Y/N) is likely to draw fewer “yes” responses than a series of questions specifically designed to jog the person’s memory of past events (e.g., Have you ever experienced a blow to the head that left you dazed and confused in a car crash? In a fall from a high place or down stairs? In a fight? In a backyard or playground accident? Etc).
- **The age of the youth in the sample:** The obvious fact is that the older the youth is the more chance he/she has had to have experienced a brain injury. Prevalence of TBI, therefore, in a study of 12-14-year olds, other factors being equal, will be lower than in a study of 17-18-year olds.
- **The level of presumed violence of the crimes committed:** For example, in a group of death row inmates convicted of murder prior to the age of 18, Lewis and colleagues (2004) found that an astounding 94% had experienced a TBI prior to their crime. In contrast, Hux and colleagues (1998) found that “only” 50% of youth offenders in their study had experienced a TBI. Why the lower prevalence in the Hux than in the Lewis study? The fact that none of the “delinquents” in the Hux study were on death row indicates less violent crimes; and TBI is known to be associated with more criminal violence than is found in non-TBI samples (Williams et al., 2010, 2018).