Traumatic Brain Injury: Opioids and CDC TBI Projects

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CDC's Response to the Opioid Overdose Epidemic
Outline

- **What we know**
  - Brief history of the opioid overdose epidemic
  - Latest data and trends
  - Relation to TBI

- **Where we’ve been**
  - Work with states

- **Where we’re going**
  - New funding
  - TBI activities
Rapid Increase in Drug Overdose Death Rates by County

SOURCE: NCHS Data Visualization Gallery
Opioid-involved poisoning has decreased U.S. life expectancy by over 2 months from 2000-2015

12 Leading Causes of Death in 2015

- Diseases of the heart
- Malignant neoplasms
- Chronic lower respiratory diseases
- Unintentional injuries
- Cerebrovascular diseases
- Alzheimer disease
- Diabetes mellitus
- Influenza and pneumonia
- Nephritis, nephrotic syndrome, and nephrosis
- Suicide
- Septicemia
- Chronic liver disease and cirrhosis

Drug, opioid, and alcohol poisoning deaths

- Drug poisoning
- Opioid-involved poisoning
- Alcohol poisoning

SOURCE: Dowell et al., 2017
How We Got Here?

1. Pain Being Designated The Fifth Vital Sign
2. Under Appreciation of Addictive Potential of Prescription Opioids
3. Aggressive Marketing of Prescription Opioids to Clinicians
4. Clinicians Who Ran Pill Mills that Profited from Over Prescribing
5. Sophisticated Actions of Drug Traffickers to Open New Heroin Markets
6. Potency and Ease of Making, Trafficking, and Profiting from Illicit Fentanyl and Fentanyl Analogs

UNITED STATES OPIOID OVERDOSE EPIDEMIC

2018
Overlapping, Entangled but Distinct Epidemics

3 WAVES IN THE RISE IN OPIOID DEATHS

- **Wave 1:** Rise in Prescription Opioid Overdose Deaths
- **Wave 2:** Rise in Heroin Overdose Deaths
- **Wave 3:** Rise in Synthetic Opioid Overdose Deaths

**Other Synthetic Opioids:** e.g., Tramadol and Fentanyl, prescribed or illicitly manufactured

**Commonly Prescribed Opioids:** Natural & Semi-Synthetic Opioids and Methadone

Variation in Trends of Fatal Drug Overdoses

2010–2016

- A total of 47 states had an increase in their drug overdose mortality rate.
- WV had the highest absolute rate at both time points.
- NH and DC had the largest absolute rate increase – each over 25 deaths per 100,000
- ME, CT, MD, MA, NH, NJ, VT each moved up over 20 spots in the ranking of states.

SOURCE: https://www.cdc.gov/drugoverdose
Opioid Overdose ED Visits Rising

Opioid overdoses continued to increase in cities and towns of all types.*

* From left to right, the categories are:
  1) non-core (non-metro), 2) micropolitan (non-metro), 3) small metro, 4) medium metro, 5) large fringe metro, 6) large central metro.

SOURCE: CDC’s Enhanced State Opioid Overdose Surveillance (ESOOS) Program, 16 states reporting percent changes from July 2016 through September 2017.
Opioid Overdose ED Visits Rising

16 States: July 2016 – September 2017

Detecting recent trends in opioid overdose ED visits provides opportunities for action in this fast-moving epidemic.

PERCENT CHANGE
- Decrease
- Increase 1 to 24%
- Increase 25 to 49%
- Increase 50% or more
- Data unavailable

SOURCE: CDC’s Enhanced State Opioid Overdose Surveillance (ESOOS) Program, 16 states reporting percent changes from July 2016 through September 2017.
A Total of 11.4 Million Americans Misused Opioids in 2017*

4.2% of total population over age 12

**Prescription Opioids**

- 11.1 Million People
- 6.3 million hydrocodone, 3.7 million oxycodone, 245K Rx fentanyl.
- Number of prescription opioid misusers declining since 2015 when 12.5 million misusers.
- Only 22% of people with OUD involving prescription opioids received treatment.

**Heroin**

- 886K People
- A total of 81K new users – a decline of 90K users year over year.
- 56% of people with OUD involving heroin received treatment. Up from 38% in 2016

2.1 million Americans with Opioid Use Disorder (OUD)

Only 30 percent of people with OUD received specialty addiction treatment. Treatment availability increasing.

*NOTE: Includes person who misused Rx opioids and heroin

SOURCE: NSDUH, Sept 2018
RX Opioids: As dose goes up, risk of death goes up

Hazard ratio for opioid overdose death

Maximum prescribed daily dose, morphine milligram equivalents

- 1 - < 20 (reference)
- 20 - < 50
- 50 - < 100
- >/= 100

Chronic pain
Acute pain

Longer durations and higher doses of opioid treatment are associated with opioid use disorder.

Long-term opioid use is associated with longer duration of initial opioid treatment

Substance use, misuse or abuse is common pre-injury. And, this increases risk-taking behaviors linked to sustaining a TBI.

Substance use, misuse or abuse may affect course and consequences of TBI rehabilitation and long term outcomes.

Substance use, misuse, and abuse may increase over time as a result of TBI given consequences of injury – social isolation, increased impulsivity and irritability, and cognitive limitations.

Chronic pain is a common co-morbidity to a TBI & opioids commonly used to treat this pain.

Few studies examine pre-injury illicit drug use and a range of long term outcomes.

SOURCE: Taylor et al., 2003; and Kumar et al, 2018;
Effect and Dangers to Alcohol and Drug Use after TBI

- Increased risk of injuries and seizures
- Exacerbation of cognitive, behavioral, and emotional difficulties
- Potential interaction with prescribed medications
- Diminished benefits of rehab
- Others?

SOURCE: Taylor et al., 2003
OPIOIDS
Acquired Brain Injury

Opioids can cause their own form of brain injury through decreasing or temporarily suspending oxygen availability to the brain.
Chronic pain is common after TBI and opioids are frequently used to treat it

- Pain is one of the most common comorbid health issues for patients sustaining at TBI.

- Chronic pain includes back, neck, and joint pain as well as headaches.

- For military members chronic pain often presents as part of a clinical triad – TBI, pain, and psychological issues like depression or anxiety.

- Chronic pain is more prevalent in patients following a mild TBI versus a moderate or severe TBI.

- Beginning in the late 1990s, opioids were increasingly used to treat chronic pain.

SOURCE: Mihalick and Glueck, 2018; Nampiaparampil, 2008
Veterans with moderate/severe TBI and with multiple co-morbidities more likely to be on opioids long-term

- Over 20 percent of veterans with TBI and chronic pain initiated opioid therapy – including 3.5 percent long term.
- Veterans with depression, PTSD, and moderate/severe TBI had nearly 3.6 times the odds of being on long-term opioid therapy.
- A vulnerable population of veterans is at greater risk for adverse clinical outcomes
CDC North Star

VISION
Prevent opioid-related harms & overdose deaths
Pillars of CDC Activity

- **Improve data** quality and track trends
- **Strengthen state, local, and tribal efforts** by scaling up effective public health interventions
- **Supply healthcare providers with resources** to improve patient safety
- **Collaborate with public safety** to respond quicker and more effectively
- **Empower consumers** to make safe choices
CDC Overdose Prevention in States Initiative

Prescription Drug Monitoring Programs

Community, Insurer, or Health Systems Interventions

State Policy Evaluations

Rapid Response Projects
Naloxone is a drug that can reverse the effects of opioid overdose and can be life-saving if administered in time.

**Medication-assisted treatment (MAT)** for opioid use disorder (OUD) can aid in preventing repeat overdoses. MAT combines the use of medication (methadone, buprenorphine, or naltrexone) with counseling and behavioral therapies.

- Offer naloxone and training to patient’s family and friends, in case the patient has another overdose.
- Connect patients with hospital case managers or peer navigators to link them to follow-up treatment and services.
- Plan for the increasing number of patients with opioid-related conditions, including overdose, injection-related concerns, and withdrawal.

**Local Emergency Department**

**First Responders | Public Safety | Law Enforcement Officers**

- Get adequate supply and training for naloxone administration.
- Identify changes in illicit drug supply and work with state and local health departments to respond effectively.
- Collaborate with public health departments and health systems to enhance linkage to treatment and services.

**Mental Health and Substance Abuse Treatment Providers**

- Increase treatment services, including MAT for OUD.
- Increase and coordinate mental health services for conditions that often occur with OUD.

**Community-Based Organizations**

- Assist in mobilizing a community response to those most at risk.
- Provide resources to reduce harms that can occur when injecting drugs, including ones that offer screening for HIV and hepatitis B and C, in combination with referral to treatment and naloxone provision.

**Local Health Departments**

- Alert the community to the rapid increase in opioid overdoses seen in emergency departments and inform strategic plans and timely responses.
- Ensure an adequate naloxone supply.
- Increase availability and access to necessary services.
- Coordinate with key community groups to detect and respond to any changes in illicit drug use.

**Community Members**

- Connect with organizations in the community that provide public health services, treatment, counseling, and naloxone distribution.

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## Opioid Data to Action Funding Opportunity

### Surveillance Required

<table>
<thead>
<tr>
<th>Morbidity (Select 1 of 4 options)</th>
</tr>
</thead>
<tbody>
<tr>
<td>- ED Tier 1: Report every 2 weeks ($250,000 per year)</td>
</tr>
<tr>
<td>- ED Tier 2: Report every month ($215,000 per year)</td>
</tr>
<tr>
<td>- ED Tier 3: Report every quarter ($115,000 per year)</td>
</tr>
<tr>
<td>- ED Tier 4: Planning year then report every quarter ($90,000 per year)</td>
</tr>
</tbody>
</table>

### Mortality (Select 1 of 3 options)

| SUDORS Tier 1: Report w/6-12 month lag (SUDORS Base + $75,000) |
| SUDORS Tier 2: Report w/8-14 month lag (SUDORS Base + $25,000) |
| SUDORS Tier 3: Planning year then report at least every w/8-14 month lag (SUDORS Base) |

### Surveillance Innovation Project

- Rapid Opioid Overdose Death Collection (<1 month from date of death) (Additional funds of $200,000 per year)
- Additional quarterly reporting of billing ICD-10-CM codes for all ED visit (Additional funds of $50,000 per year)

### Prevention Required

<table>
<thead>
<tr>
<th>PDMP (Select one)</th>
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<tbody>
<tr>
<td>- PDMP Base: Improved PDMP functionality</td>
</tr>
<tr>
<td>- PDMP Base + Expanded: Improved PDMP functionality and intra- &amp; inter-state interoperability (Additional funds of $250,000)</td>
</tr>
</tbody>
</table>

- State & Local Integration (20% of prevention budget required to go local to communities)

### Linkages to Care

### Providers & Health Systems Support

### Optional

- Public Safety Partnerships
- Empowering Individuals
- Prevention Innovation Project
- Peer-to-Peer Learning Coordinator (Additional funds of $250,000)
Opioid Overdose Epidemic: Federal Players

CDC
CMS
Surgeon General
HHS
NIH

FDA
SAMHSA
DOL
VA
DEA
HUD
Intersections: TBI and opioids
Traumatic Brain Injury
Epidemiology of TBI

In 2014, there were approximately 2.87 million TBI-EDHDs in the United States, including over 837,000 occurring among children. This includes:

- Approximately 2.53 million TBI-related ED visits, including over 812,000 occurring among children.
- Approximately 288,000 TBI-related hospitalizations, including over 23,000 occurring among children.
- 56,800 TBI-related deaths, including 2,529 occurring among children.

The number of total TBI-EDHDs increased by 53% from 2006 (N approximately 1.88 million) to 2014 (N approximately 2.88 million).

https://www.cdc.gov/traumaticbraininjury/data/
https://www.cdc.gov/traumaticbraininjury/data/
Ages estimates based on ED visits

Ages 65 + years

Ages 0-4 Years

Ages 15-24 years
Where Are Most Youth Concussions First Diagnosed?

Point of Entry Data from The Children's Hospital of Philadelphia show the vast majority of youth concussions are diagnosed in a primary care setting.

- Primary Care: 82%
- ED/Urgent Care: 12%
- Specialty Outpatient: 5%
- Hospital Inpatient: 1%

Variation in Mechanism of Injury by Age in Children

- SRR injuries in children older than 5 years contributed to the majority of concussions
- Approximately 30% of concussions were Non-SRR
- Higher proportions for younger children

Sports and Recreational Injuries in Children

- An estimated 283,000 children seek care in U.S. emergency departments each year for a sports- or recreation-related traumatic brain injury (SRR-TBI), according to a new MMWR Report.
- Contact sports contributed to nearly half (45%) of the SRR-TBI visits examined.
- Activities with the highest number of SRR-TBI visits included: football, bicycling, basketball, playground activities, and soccer.

Source: https://www.cdc.gov/mmwr/volumes/68/wr/mm6810a2.htm?s_cid=mm6810a2_w
National Estimate of Parent Reported TBI

Estimate by parent report was 2.5% of US Children who have a history of TBI in the US

Health Conditions Associated with a Lifetime History of TBI

<table>
<thead>
<tr>
<th>Condition</th>
<th>Lifetime History of TBI</th>
<th>No Lifetime History of TBI</th>
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</thead>
<tbody>
<tr>
<td>Learning Disorder</td>
<td>21%</td>
<td>9%</td>
</tr>
<tr>
<td>ADHD</td>
<td>20%</td>
<td>8%</td>
</tr>
<tr>
<td>Speech/Language Problems</td>
<td>19%</td>
<td>8%</td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>15%</td>
<td>5%</td>
</tr>
<tr>
<td>Bone, joint or muscle problems</td>
<td>14%</td>
<td>3%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>13%</td>
<td>4%</td>
</tr>
<tr>
<td>Depression</td>
<td>11%</td>
<td>3%</td>
</tr>
<tr>
<td>Behavior Problems</td>
<td>8%</td>
<td>2%</td>
</tr>
<tr>
<td>Hearing Problems</td>
<td>7%</td>
<td>3%</td>
</tr>
</tbody>
</table>
Influencing care for children

Law includes 3 components of Education, Removal from play and Return-to-play
Pediatric Mild TBI Guidelines
Pediatric mTBI Guideline

- Published in September 2018
- Prior to CDC’s Pediatric mTBI Guideline release, there had been consensus-based guidelines on pediatric mTBI, but no evidence-based clinical guidelines for healthcare providers.
SNAPSHOT: CDC Pediatric mTBI Guideline

The Guideline is:

- The most comprehensive review of pediatric mTBI scientific evidence to-date – **summarizing 25 years of scientific research**
- The only U.S. evidence-based clinical recommendations for healthcare providers that:
  - Covers all causes of pediatric mTBI
  - Includes guidance for:
    - Primary care
    - Outpatient specialty
    - Inpatient care
    - Emergency care settings
SNAPSHOT: Clinical Recommendations

• **19 recommendations sets** covering diagnosis, prognosis, and management and treatment

• Five practice-changing recommendations:
  1. **No routine imaging** of patients with suspected mTBI for diagnostic purposes
  2. Use validated, age-appropriate **symptom scales** to diagnose mTBI
  3. Assess evidence-based **risk factors for prolonged recovery**
  4. Provide patients with instructions on return to activity **customized to their symptoms**
  5. Counsel patients to return gradually to non-sports activities after no more than a **2-3 days of rest**
Getting this Information into Practice
Implementation Tools

**For Healthcare Providers**
- Checklist on diagnosis and management
- Screening/Assessment tools (acute and primary care setting)
- Online training with continuing education opportunity—new
- EHR module (if possible)—new
- At-a-glances (overview of key recommendations)—new

**For Parents**
- Discharge instructions—new
- Symptom-based recovery tips handout—new
- Existing CDC HEADS UP content *(see next slide)*
September 2018

CDC'S GUIDELINE ON
Diagnosis and Management of Mild
Traumatic Brain Injury Among Children

25 YEARS OF SCIENTIFIC
RESEARCH EXAMINED

19 SETS OF CLINICAL
RECOMMENDATIONS
CREATED

Learn how to improve the care of your
young patients: www.cdc.gov/HEADSUP

www.cdc.gov

CDC HEADS UP
SAFE BRAIN. STRONGER FUTURE.

CDC PEDIATRIC mTBI GUIDELINE
Diagnostic Recommendations

GOAL OF THE CDC mTBI GUIDELINE
The goal of the CDC mTBI guidelines is to provide recommendations to healthcare professionals for the diagnosis and management of mild traumatic brain injury (mTBI) in children and adolescents. These guidelines include recommendations for the diagnosis and management of mTBI in children, as well as recommendations for the prevention of mTBI.

RECOMMENDATIONS FOR THE DIAGNOSIS OF mTBI
The key recommendations for the diagnosis of mTBI in children include: (1) Obtain a thorough history and physical exam, (2) Consider using imaging tests, and (3) Consider using other diagnostic tools.
Updated *HEADS UP to Healthcare Providers Training*

- Part of the HEADS UP concussion education initiative
- Process of updating and rebranding
  - Current scientific findings
  - Pediatric guideline recommendations
- Free continuing education credits
National Center for Injury Prevention and Control

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Service Delivery in the Healthcare and Educational Systems for Children Following Traumatic Brain Injury: Gaps in Care

Juliet Haarbauer-Krupa, PhD; Angela Ciccia, PhD; Jonathan Dodd, PhD; Deborah Eitel, PhD; Brad Kurouwski, MD; Angela Lumba-Brown, MD; Stacy Suskauer, MD

Objective: To provide a review of evidence and consensus-based description of healthcare and educational service delivery and related recommendations for children with traumatic brain injury. Methods: Literature review and group discussion of best practices in management of children with traumatic brain injury (TBI) was performed to facilitate consensus-based recommendations from the American Congress on Rehabilitation Medicine’s Pediatric and Adolescent Task Force on Brain Injury. This group represented pediatric researchers in public health, medicine, psychology, rehabilitation, and education. Results: Care for children with TBI in healthcare and educational systems is not well coordinated or integrated, resulting in increased risk for poor outcomes. Potential solutions include identifying at-risk children following TBI, evaluating their need for rehabilitation and transitional services, and improving utilization of educational services that support children across the lifespan. Conclusion: Children with TBI are at risk for long-term consequences requiring management as well as monitoring following the injury. Current systems of care have challenges and inconsistencies leading to gaps in service delivery. Further efforts to improve knowledge of the long-term TBI effects in children, child and family needs, and identify best practices in pathways of care are essential for optimal care of children following TBI. Key words: children, education, healthcare, rehabilitation, traumatic brain injury

Pediatric Traumatic Brain Injury (TBI) is a chronic health condition with effects that can extend beyond the time of initial medical care and impact neurobehavioral development and overall health. Child development is complex, encompassing physical, psychosocial, and cognitive aspects coupled with increased environmental expectations for more sophisticated behavior. Neurologic injury secondary to trauma in childhood can affect these key phases of development with resulting long-term effects requiring specialized, acute, and long-term management. Therefore, addressing the needs of pediatric TBI survivors requires dedicated efforts across both healthcare and educational systems; however, the provision and coordination of these services are complicated. Current services are insufficient because there is often a discrepancy between the need for pediatric rehabilitation and school services, which often leads to gaps in service delivery.
What we know about TBI across the Lifespan
Report to Congress

- Identifies gaps in health care, school, and community services

- Highlights policy strategies to address the short and long-term consequences of a TBI

- Offers **specific and actionable recommendations** to improve TBI care in children, and advance our understanding of TBI care in the future
Report to Congress

- TBI Act of 2014
  - The United States Congress directed CDC, in consultation with the National Institutes of Health to: “conduct a review of scientific evidence related to brain injury in children and submit a Report to Congress that describes the results and makes recommendations”

- Released in March 2018
Medical Management of Pediatric Traumatic Brain Injury
Take Home Points: Medical Management

- Consistent Guideline implementation across healthcare providers needed
- TBI as a chronic disease in children
- There are frequently unmet needs after hospital discharge
  - Neurocognitive, behavioral, academic, social
- Motor and balance problems may be more subtle
- Not a clear definition of recovery and how to assess/determine objectively
- “Silent” problems occur in complex settings and return to “real world”
- Interplay among pre-injury health/behavior and post-injury recovery is important
- Consistent and regular assessments are important
Link between Medical Community and School

- Communication between medical system and school/community is not consistent
  - Better if children enrolled in in-patient Rehab (Glang et al 2014).
- Resources such as school intervention coordinators are variable
- Medical records not always easily accessible by the school
- Injury may not be reported to school, especially if mild
Family and Parent Support

- Families experience significant stress after the injury
- Unexpected alteration in child’s health, development, and behavior
- Providing parents with information about TBI can alleviate stress
- Parental support and training is often lacking, but may be helpful
- Family focused therapy programs are underutilized
- Problem solving therapy has been helpful

Return to Play and Activity for Children

- Return to play legislation primarily focused on organized sports
- Consensus guidelines for return to organized sports in place
- Lack of universal progression for all sports, e.g., contact versus non-contact
- Variability in how return to play guidelines are interpreted and implemented
- Return to driving protocols lacking
- Return to activities guidelines for younger children (e.g., < 5 years) lacking
Educational Services
Educational Outcomes and Needs

- Outcomes for children with moderate-severe TBI:
  - Worse grades
  - Higher rates of grade retention
  - More often need special education

- 14% of children with mTBI needed supports at school (Rivara et al., 2012)

- Students with mild-complicated/moderate TBI had increased need for supports over time (Prasad et al., 2016)
Long Term Outcomes

- Low rates of:
  - Enrollment in post-secondary education
  - Employment
  - Independent living

(Cameto, Levine & Wagner, 2004)

- High rates of criminal behavior and incarceration

(Chitsabesan, Lennox, Williams, Tariq, & Shaw, 2015; McKinlay, Ligteringin, & Than, 2013)
Educational Supports

- Early intervention services (IDEA, Part C)
- Special education (IDEA)
- Section 504 (Rehabilitation Act of 1973)
- Transition services (IDEA)

Schools focus on learning.....
Gaps in Educational Services

- Services for preschool children
- Family education on the impact of TBI on school
- Injuries may be forgotten over time
- Children may receive services under different disability labels
- State directors of special education: Only 40% of students with TBI are classified under the TBI category (Glang, Ettel, Todis et al. 2015)
- Education and training for educators
- The need for academic services among patients who sustained a TBI during early childhood remains high 6 years post injury (Kingery, Narad, Taylor et al., 2017)
Promising Practices

- Healthcare-educational linkages to improve access to school services
- School-based brain injury management teams
- Evidence-based training for all members of school community
Report to Congress Recommendations

- **Return to School**
  - Ensure that all children who return to school following a TBI are monitored
  - Need for coordination of care across settings (medical, educational)
  - Training for educational professionals

- **Transitions**
  - From elementary to middle to high school
  - From pediatric to adult healthcare

- **Research**
  - Need for longitudinal studies
  - More comprehensive surveillance estimates
Recognize.
Monitor.
Care.

Report to Congress on the Management of Traumatic Brain Injury in Children
The National Center for Injury Prevention and Control at the Centers for Disease Control and Prevention (CDC) is looking for school re-entry programs designed to help children return to their learning environment after concussion and other traumatic brain injury (TBI).

What Can I Expect When I Submit a Nomination?

As part of the nomination process, you’ll tell us about how your program is currently working, what kinds of evaluation support are needed, and what types of CDC services and products could be beneficial. All nominated programs will receive brief feedback from CDC to inform future evaluation activities. This is an opportunity for your program to contribute to this field of practice by sharing your experience. In addition, you’ll be getting free, expert program evaluation advice from CDC.

Special Benefits for Outstanding Programs

Two to four promising programs will be selected for site visits and intensive evaluation assistance. These programs may:

- Receive on-site consultation for program improvement and evaluation design.
- Receive a comprehensive written description of program design and operations.
- Be featured by CDC and/or other organizations as a model program.
- Help identify the characteristics of practice-based strategies and interventions that contribute to program effectiveness.
- Be considered for a future comprehensive evaluation.

What Kinds of Programs Will Be Considered for the Project?

Programs run by schools, health care, state agencies, or other organizations will be considered for this project. We are seeking nominations of established return to learn (RTL) programs that aim to accomplish one or more of the following:

- Address the medical and educational needs of students with concussion or other TBI as they resume learning after injury.
- Implement various strategies to assist school-aged children with concussion and other TBI.
- Have procedures in place for adaptations to the student’s learning environment while the brain heals and symptoms resolve, as needed.
Background

- Project initiated from examination of Concussion Legislation in 50 states
  - 8 States have RTL mentioned in their legislation

- Background Projects examining Return to Learn
  - Examination of Legislation Components in 50 States
  - Qualitative interviews about RTL practices
  - Informational Meeting in December 2016
  - Examining the conflation of RTL and IDEA Legislation

- From the Evaluability Process
  - Return to School programs currently occur in various settings:
    - Schools
    - Health care
    - State agency/Non-profit
Identification of TBI

- **Healthcare**
  - Diagnosis by a healthcare provider-based on CDC definition/ICD-CM codes
  - Current data is from Emergency Department visits
  - Some children are seen by a pediatrician or family practitioner, especially for mild injuries.
  - In some settings the athletic trainer makes the initial diagnosis

- **School**
  - PARENT OR STUDENT REPORT
  - Discharge letter or information from healthcare visit conveyed to school
  - Teacher report of a change in student behavior
  - Observation of a TBI event at school

EVENT OCCURRED BUT DID NOT SEEK MEDICAL CARE
Project Purpose

Project Goals

Identify potentially promising RTL programs in the field

Based on expert review, systematically select and conduct evaluability assessments with select RTL programs

Identify program(s) ready and appropriate for rigorous evaluation

When possible, provide technical assistance and feedback to nominated RTL programs to improve program implementation and build evaluation capacity

CDC is also interested in…

How to reach all ages of children with TBI

Making sure that TBI from all injury mechanisms is identified and managed

How to learn more about student follow-up and outcomes

What is the best program model or model components for understanding youth outcomes?

Scalability and applicability for all 50 states in the US-to ensure care consistency
Map of Nominations Received
The Systematic Screening and Assessment (SSA) and Evaluability Assessment (EA) Process
The RTL SSA Process

Nomination Review
First External Review
Site Visits
Second External Review

Is intervention promising?
Yes

Does intervention have program design integrity and realistic, achievable goals?
Yes

Is intervention implemented as intended and at an appropriate developmental level?
Yes

To answer questions: (1) Is there a feasible design? (2) Are data available or feasible to collect?
Yes

Evaluable Intervention

Assist in improvement of program design, implementation, and evaluation characteristics
Sites Visited

Concussion Institute
Gwinnett Medical Center
Duluth, GA

The Concussion Management Team

Lincoln Public Schools
Themes and Lessons Learned
## Models of Care

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<tr>
<th>Role/Aspect</th>
<th>Medical</th>
<th>Educational</th>
<th>State Agency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leader</td>
<td>Physician</td>
<td>Teacher or Educational Team</td>
<td>State Lead Agency; Advocacy Group</td>
</tr>
<tr>
<td>Purpose</td>
<td>Health and recovery</td>
<td>Learning and academic achievement</td>
<td>Case Management and Coordination</td>
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<tr>
<td>Funding</td>
<td>Fee for service based on insurance coverage</td>
<td>Teacher Salaries and stipend from federal, state or local system funds</td>
<td>State Agency Grants; Federal Grants (HRSA, ACL); TBI Trust Funds</td>
</tr>
<tr>
<td>Information Sharing Requirements</td>
<td>HIPPA</td>
<td>FERPA</td>
<td>HIPPA and FERPA</td>
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<tr>
<td>Service Guidance</td>
<td>Medical Necessity</td>
<td>Maintaining a student in an educational program</td>
<td>Case management (intermediary)</td>
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<tr>
<td>Services</td>
<td>Therapies (PT-OT-SLP), vision, psychology, neuropsychology, educational liaison</td>
<td>Therapies (PT-OT-SLP), school psychology, school counselor, school nurse</td>
<td>Resources for services</td>
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<tr>
<td>Qualification for services</td>
<td>Medically necessary/insurance approval</td>
<td>TBI event and symptoms-CMT. Verified for Special education</td>
<td>Documentation of TBI</td>
</tr>
<tr>
<td>Length of services</td>
<td>Based on therapy caps</td>
<td>Determined by symptoms or learning needs</td>
<td>Determined by need and available resources</td>
</tr>
</tbody>
</table>
Lessons Learned: Healthcare

- Medical expertise on TBI
- Physician Champion
- Electronic Health Records can ensure consistency in care across clinics and practices
- Specifying medical appointment follow-up
- Availability of multiple medical specialties
- Many pediatric healthcare settings have established procedures for covering children who need services and are uninsured or underinsured
Lessons Learned: School

- Ownership for learning
- Existing procedures for helping students with medical conditions: school nurse, 504 plans and Special Education Individualized Plans (IEPs)
- Tracking students on an annual basis
- Local school systems connected to State Department of Education
- Planned communication with parents
- Electronic School Records
Lessons Learned: State

- TBI Lead Agencies
- TBI Trust Funds
- State Department of Education
- School models for specialized service delivery
- State Chapters of Advocacy Groups
  - BIAA and USBIA
Promising Practices: Overall

- Parent Involvement
- Return to School Program Communication and Collaboration addressing all age groups and TBI severity.
  - Forms for healthcare providers to provide discharge instructions
  - Offering guidance for return to activities - school, sports and recreation
- Partnering with academic institutions and other TBI stakeholders
- Using evidence to form policies and practices
Policy and Legislative Impact

Return to Play and Return to Learn Laws

School Health Plan

Special Services Laws
- 504 plans
- Special Education Laws
Adults with TBI
CDC Resources for Adults

https://www.cdc.gov/traumaticbraininjury/symptoms.html
• Work conducted is consistent with the mission of both agencies

• Conduct studies utilizing the TBIMS National Dataset
  – Rehabilitation outcomes
  – Prevalence of disability
  – Participation limitations

• Opportunity to widely disseminate research findings, following a public health approach
Interagency Agreement between CDC and NIDILRR

- NIDILRR’s TBIMS-ND representative of the U.S. Population of patients ages 15-64 who received acute rehabilitation with a primary diagnosis of TBI
- Longitudinal Design with more than 11,000 patients enrolled
- Follow-up interviews using standardized instruments
  - 1 year, 2 years and 5 years post injury
  - 5 years every year thereafter
- Initial Enrollees are receiving 20 year follow-up interviews
- Products include
  - Manuscripts
  - Symposiaums
  - Policy-focused products
Representativeness of the Traumatic Brain Injury Model Systems National Database

John D. Corrigan, PhD; Jeffrey P. Cuthbert, MPH, MS; Gale G. Whiteneck, PhD; Marcel P. Dijkers, PhD; Victor Coronado, MD, MPH; Allen W. Heinemann, PhD; Cynthia Harrison-Felix, PhD; James E. Graham, PhD

Epidemiology of Adults Receiving Acute Inpatient Rehabilitation for a Primary Diagnosis of Traumatic Brain Injury in the United States

Jeffrey P. Cuthbert, PhD, MPH, MS; Cynthia Harrison-Felix, PhD; John D. Corrigan, PhD; Scott Kreider, MS; Jeneita M. Bell, MD, MPH; Victor G. Coronado, MD, MPH; Gale G. Whiteneck, PhD

Life Expectancy following Inpatient Rehabilitation for Traumatic Brain Injury in the United States

Cynthia L. Harrison-Felix, Christopher R. Pretz, Flora Hammond, Jeffrey Cuthbert, Jeneita Bell, John D. Corrigan, A.Cate Miller, Juliet Haarbauer-Krupa


Jeffrey P. Cuthbert, MPH, MS; John D. Corrigan, PhD; Gale G. Whiteneck, PhD; Cynthia Harrison-Felix, PhD; James E. Graham, PhD; Jeneita M. Bell, MD, MPH; Victor G. Coronado, MD, MPH

US Population Estimates of Health and Social Outcomes 5 Years After Rehabilitation for Traumatic Brain Injury

John D. Corrigan, PhD; Jeffrey P. Cuthbert, PhD, MPH, MS; Cynthia Harrison-Felix, PhD; Gale G. Whiteneck, PhD; Jeneita M. Bell, MD, MPH; A. Cate Miller, PhD; Victor G. Coronado, MD, MPH; Christopher R. Pretz, PhD
Functional Outcome Trajectories Following Inpatient Rehabilitation for TBI in the United States: A NIDILRR TBIMS and CDC Interagency Collaboration

Kristen Dunn-O’Connor, PhD; Jessica M. Ketchum, PhD; Jeffrey P. Colburn, PhD; John D. Corrigan, PhD; Flora M. Henderson, MD; Juliet Hasbrouck-Kropp, PhD; Robert G. Kovlacks, MIRCH, MS; A. Cate Miller, PhD

Objective: To describe trajectories of functioning up to 5 years after traumatic brain injury (TBI) that required inpatient rehabilitation in the United States using individual growth curve models combined with factors associated with individual-level outcomes identified from a study of 1,786 individuals using data from a multisite longitudinal cohort study. Setting: Acute inpatient rehabilitation facilities. Participants: A total of 645 individuals 15 years and older with a primary diagnosis of TBI. Main Outcome Measures: Ratings of global disability and supervision needs as reported by participants or proxy during follow-up telephone interviews at 1, 2, and 3 years postinjury. Results: Many TBI survivors experience functional improvement through 1 and 2 years postinjury, followed by a decline in functioning and decreased independence by 5 years. However, there was considerable heterogeneity in outcomes across individuals. Factors such as older age, lower premorbid productivity, public payer source, longer length of inpatient rehabilitation stay, and lower discharge functional status were found to negatively impact trajectories of change over time. Conclusion: These findings can inform the content, timing, and target recipients of interventions designed to maximize functional independence after TBI. Key words: disability, independence, longitudinal data analysis, outcomes, rehabilitation, traumatic brain injury.
One and Five Year Outcomes after Moderate to Severe TBI Requiring Inpatient Rehabilitation

Purpose: To describe long term functional outcomes after Moderate to Severe TBI in Adults

Available at: https://www.cdc.gov/traumaticbraininjury/pdf/CDC-NIDILRR-Self-Report-508.pdf
Moderate to Severe Traumatic Brain Injury is a Lifelong Condition

Five-year outcomes of persons with TBI

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Died</td>
<td>22%</td>
</tr>
<tr>
<td>Worse</td>
<td>22%</td>
</tr>
<tr>
<td>Same</td>
<td>30%</td>
</tr>
<tr>
<td>Improved</td>
<td>26%</td>
</tr>
</tbody>
</table>

Long-term negative effects of TBI are significant.

After inpatient rehabilitation for TBI, the following groups are more likely to die sooner:
- Older adults
- Men
- Unemployed
- People who are not married
- People with fewer years of education
- People with more severe TBI
- People with fall-related TBI

Policy Implications: Proactive Management of TBI

With proper health care and community services, some causes of TBI-related problems can be prevented or treated, and the impact can be reduced. Because the problems faced by people with TBI are lasting, they require long-term solutions. While coordinated approaches to acute care and rehabilitation after TBI are available, only a few promote long-term health and well-being. The public health burden of TBI suggests important implications for future policies to address proactive, lifelong disease management.

TBI researchers and the TBI Model System Program should continue to:
- Study TBI as a chronic health condition.
- Investigate the contribution of pre-existing and co-occurring conditions.
- Identify risk factors, such as sleep, weight, depression, aging, and alcohol use.
- Study the benefits of exercise, diet, social support, and engagement in the community.
- Test treatments for depression, irritability, sleep disorders, and cognitive impairment.

At the federal level, decision-makers can:
- Recognize TBI as a chronic health condition.
- Address policies that affect access to rehabilitation services over the life span.
- Integrate research that addresses the future management of TBI.
- Enhance surveillance to monitor the national burden of TBI.

At the state level, decision-makers can:
- Identify the prevalence of disabilities due to TBI among its residents.
- Screen for TBI history among persons who receive state-funded health and social services.
- Alleviate health and social service professionals to recognize and minimize the effects of TBI on behavior.
- Make home and community services more accessible to people with TBI.

Health care providers can:
- Determine if their patients have experienced TBI and understand the impact of TBI on the current health status of patients.
- Screen and treat common, late-developing problems, such as depression, substance misuse, and weight gain.
- Encourage lifestyles that promote brain health.
- Educate patients and their families to prevent or reduce late-onset problems.

Available at: https://www.cdc.gov/traumaticbraininjury/pubs/index.html
Moderate and severe traumatic brain injury (TBI) can lead to a lifetime of physical, cognitive, emotional, and behavioral changes. These changes may affect a person’s ability to function in their everyday life. Despite initial hospitalization and inpatient rehabilitation services, about 50% of people with TBI will experience further decline in their daily lives or die within 5 years of their injury. Some of the health consequences of TBI can be prevented or reduced. Attending to these lifelong issues also known as chronic disease management, is crucial for improving the lives of persons with TBI.

This fact sheet outlines the estimated burden of moderate and severe TBI on public health, and highlights key policy strategies to address the long-term consequences of TBI. The national estimates are based on data from the TBI Model Systems (TBIMS) National Database. It contains data from the largest study of people with moderate or severe TBI who receive inpatient rehabilitation, and includes information from the time of injury to the end of life. Those requiring inpatient rehabilitation are among the most severely injured and constitute less than 10% of all persons hospitalized with a TBI.

Five-year outcomes of persons with TBI

- 22% Died
- 30% Became Worse
- 22% Stayed Same
- 26% Improved

Data are US population estimates based on the TBIMS National Database. Data refer to people 16 years of age and older who received inpatient rehabilitation services for a primary diagnosis of TBI.
**Long-term negative effects of TBI are significant.**

Even after surviving a moderate or severe TBI and receiving inpatient rehabilitation services, a person’s life expectancy is 9 years shorter. TBI increases the risk of dying from several causes. Compared to people without TBI, people with TBI are more likely to die from:

<table>
<thead>
<tr>
<th>Condition</th>
<th>Likelihood</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seizures</td>
<td>50 x more likely</td>
</tr>
<tr>
<td>Accidental Drug Poisoning</td>
<td>11 x more likely</td>
</tr>
<tr>
<td>Infections</td>
<td>9 x more likely</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>6 x more likely</td>
</tr>
</tbody>
</table>

**After inpatient rehabilitation for TBI, the following groups are more likely to die sooner:**

- Older adults
- Men
- Unemployed
- People who are not married
- People with fewer years of education
- People with more severe TBI
- People with fall-related TBI

In addition, people with moderate to severe TBI typically face a variety of chronic health problems. These issues add costs and burden to people with TBI, their families, and society. Among those still alive 5 years after injury:

- **57%** are moderately or severely disabled.
- **55%** do not have a job (but were employed at the time of their injury).
- **50%** return to a hospital at least once.
- **33%** rely on others for help with everyday activities.
- **29%** are not satisfied with life.
- **29%** use illicit drugs or misuse alcohol.
- **12%** reside in nursing homes or other institutions.
Policy Implications: Proactive Management of TBI

With proper health care and community services, some causes of TBI-related problems can be prevented or treated, and the impact can be reduced. Because the problems faced by people with TBI are lasting, they require long-term solutions. While coordinated approaches to acute care and rehabilitation after TBI are available, only a few promote long-term health and well-being. The public health burden of TBI suggests important implications for future policies to address proactive, lifelong disease management.

Coordinated long-term care can help prevent or reduce many costly consequences of TBI, such as:
- Decreased life expectancy
- Poor health
- Limited function
- Low quality of life

TBI researchers and the TBI Model System Program should continue to:
- Study TBI as a chronic health condition.
- Investigate the contribution of pre-existing and co-occurring conditions.
- Identify risk factors, such as sleep, weight, depression, aging, and alcohol use.
- Study the benefits of exercise, diet, social support, and engagement in the community.
- Test treatments for depression, irritability, sleep disorders, and cognitive impairment.
For more information, contact CDC
1-800-CDC-INFO (232-4636)

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.