

Research Summary and References

Support for the Toolkit

TOOLKIT

This toolkit, and specifically the *Concussion Management Protocol*, were developed based on the research summarized below. The research supports educating practitioners (rationale for the **Reference** section), properly evaluating, monitoring and referring patients (rationale for the **In-Office** section) and properly educating those with mTBI/ TBI (rational for the **Send-Home** sections).

CHILDREN:

Healthcare providers outside hospitals are on the front lines:

Most (82%) of those 0 to 17 years will seek initial care with their primary care physician (Arbogast, et al., 2016). Since most of our incidence data comes from Emergency Department's (ED's), we are significantly underestimating the extent of the TBI issue (Study included over 8,000 patients).

The very young are frequently not diagnosed or treated:

The newest pediatric mTBI guidelines recommend using an age-appropriate validated concussion scale (Lumba-Brown, et al., 2018), but one does not exist yet that focuses on children five and under. We must look for additional signs in children five years and under. For this age range, parents endorse the typical symptoms from the ACE, but in answer to an open-ended question, 82% also reported additional symptoms (Suskauer, et al., 2018), including:

- * Appetite changes
- * Behavioral dysregulation
- * Decreased engagement
- * Disrupted sleep
- * Bladder incontinence (Enuresis)
- * Increased dependence
- * Stomachaches

The study also concluded that it is important to monitor behavior dysregulation over time. At first, parents saw disengagement, and then behavior dysregulation emerged and persisted. Behavioral dysregulation was among most commonly reported symptoms and was still present at the time of the evaluation (over one month post).

Children with TBI may develop or have ongoing concerns and should be monitored (for years):

They are more likely to have a variety of health/academic issues compared to those with no TBI (Haarbauer-Krupa, Lee, et al., 2018). The highest prevalence are:

- * Learning disorders
- * ADD/ADHD
- * Speech Language problems
- * Developmental delay
- * Anxiety
- * Bone, joint or muscle problems

Children with mild (Taylor, 2015) and moderate and severe (Schwartz, 2003) injuries are more at risk for persistent behavior problems. The risk rises with severity of the mTBI and younger age at injury. Even in children whose injuries were significant enough to show skull or brain tissue damage on imaging, only one-fourth received any rehabilitations services afterward and only one-fourth received a neuropsychological assessment. None of the children received early intervention or special education preschool services after their TBI (Haarbauer-Krupa, Lundine, et al., 2018). This study concludes:

- * Healthcare providers should provide information to parents on what to watch for and long term implications.

- * Healthcare providers should make appropriate referrals at the time of diagnosis.
- * Referral to rehabilitation can help with transition to preschool.

Another study (Niedzwecki, et al., 2018) concluded that even though children did not receive inpatient care, some will still benefit from rehabilitation for subsequent problems, including memory and learning issues (that were not pre-existing).

This study also found that medical issues at the time of injury, like elevations or depressions of Intra-cranial pressure (ICP), unstable blood pressure, unstable oxygenation, delayed nutrition or seizures, can impact the child's IQ at 12 months.

- * The study's recommendation for trauma treatment is that rehab services be included early in the continuum – this would include consultation early in the ICU or acute care settings and referrals to an outpatient concussion clinic.

In the first year after injury, a substantial portion of children with moderate or severe TBI have unmet or unrecognized healthcare needs, with cognitive services being most frequent among these. Because of this finding, the authors recommended that cognition be screened in the primary care setting (Slomine, et al., 2006).

Reason for unmet needs:

- * Lack of a physician's recommendation or referral
- * Failure of parent follow-up
- * Not provided in the school settings
- * Cost

Children with all levels of impairment had educational needs, while those with less severe injuries were at greater risk of being underserved (Kingery, et al., 2017).

Earlier age at time of injury produces more functional impairment (Taylor, et al., 2015). The more severe the injury and the younger age at injury, the greater the need for monitoring and follow up (Anderson, Catroppa, Dudgeon, 2006; Anderson, Catroppa, Haritou, 2006).

On the first visit, provide educational materials, accommodations for return to school and recommend a follow up visit (at which time appropriate referrals can be made):

- * Many children did not even visit a healthcare provider in the year following their injury (Slomine, et al., 2006).

Ongoing family support is important:

Family support is important because those with family dysfunction/poor coping, the child had greater dysfunction (Schwartz, 2003; Anderson, Catroppa, Dudgeon, et al., 2006; Taylor, 2008).

Families also reported needing information, emotional support and access to community-based services (Jones, 2017).

Schools need the support/recommendations of healthcare providers:

Teachers are not adequately trained to identify brain injuries and issues related to them (Davies, et al., 2013).

On specialized testing, children with TBI tend to show specific patterns of deficit that will not be revealed through standard special education testing. A neuropsychological evaluation will pick up these patterns. In a study of mild complicated TBI (with orthopedic controls), children who were injured before age 6 and were about 5 years post injury were tested. Both groups were within normal limits on most cognitive, language and reading measures; but they had some differences in verbal IQ, receptive

language and reading comprehension. The biggest differences were in pragmatic language (which leads to social issues), story retell, and word fluency (Haarbauer-Krupa, King, et al., 2019).

Schools will not provide all of what a child needs (Niedzwecki, 2018). Schools are only required to provide those services that directly relate to academics.

The gap in academic achievement widens over time (compared with non-injured classmates) (Ewing-Cobbs, 2006; Farmer, 1997; Taylor & Yeates, 2002; Todis & Glang, 2008; Todis, Glang, Bullis, et al., 2011; Wagner, et al., 2006). So, if children with TBI do not qualify for services at first, they should be referred again if they continue to have difficulties.

“Children who receive systematic transition services a part of their medical care are more likely to be identified for specialized support services at school, such as speech therapy (Haarbauer-Krupa, Ciccio, et al., 2017).

Use of the ACE tools (screening tool and Care Plan) “increased patient follow-up and improved recall of and adherence to ED discharge recommendations (Zuckerbraun, 2014).”

Pediatric Guideline:

Also see the CDC Pediatric Guideline (Lumba-Brown, et al., 2018) on mTBI in this toolkit for 19 sets of recommendations, with these [5 key take away points](#):

1. Do not routinely image pediatric patients to diagnose mTBI.
2. Use validated, age-appropriate symptom scales to diagnose mTBI.
3. Assess risk factors for prolonged recovery, including history of mTBI or other brain injury, severe symptom presentation immediately after the injury, and personal characteristics and family history (such as learning difficulties and family and social stressors).
4. Provide patients and their parents with instructions on returning to activity customized to their symptoms.
5. Counsel patients and their parents/caregivers to return gradually to non-sports activities after no more than 2-3 days of rest.

Consequences of brain injury for all ages:

Once a person has one brain injury, the risk for another increases, and the risk increases with each subsequent injury. A person with a brain injury is also more likely to be incarcerated (or involved with the criminal justice system) (Farrer & Hedges, 2011; Shiroma, et al., 2012; Williams, et al., 2010; Im, et al., 2014), to have psychiatric issues ((McCarthy, et al., 2006; Kaponen, et al., 2002; Zgaljardic, et al., 2015), to be involved with substance abuse (Kreutzer, et al., 1996), and to be socially isolated (Morton & Wehman, 1995; Hawthorne, et al., 2009). Long-term psychiatric disorders are associated with greater risk for substance abuse (Zgaljardic, et al., 2015). Prior TBI has been identified as a potential contributing factor to domestic violence (Romero-Martinez & Moya-Albiol, 2013). Not surprisingly, TBI is found in female victims of domestic violence (Corrigan, et al., 2001).

ADULTS

Follow up and education are important:

Findings from a study (Seabury, et al., 2018) of follow-up care that was provided to people at 11 Level 1 trauma centers across the country:

- * Less than half received TBI educational material at discharge or saw a health care practitioner within 3 months after injury.
- * Only 27% were called by 2 weeks.
- * Follow-up care varied by site, from 19% to 72%.

- * For those with a positive CT scan, over one-third had not seen a medical practitioner for follow-up.
- * Even among those with 3 or more moderate to severe post-concussive symptoms, only about half saw a medical practitioner within 3 months.
 - o Of those that did, 80% reported that it was helpful. The majority saw a general practitioner and 38% saw a neurologist. Only 15% reported visiting a clinic specializing in TBI care.

A few conclusions from the paper:

- * “Failure to follow-up with patients could have adverse consequences, as simply providing educational materials to patients with mTBI is associated with improved outcomes.”³⁵
- * “Our findings reveal the consequences that may result from the absence of systems of follow-up care for patients with mTBI and concussion. They also highlight an apparent lack of appreciation by many clinicians of the substantial symptom and life burdens experienced by a significant proportion of patients with injuries labeled mild.”

Use of the ACE tools (screening tool and Care Plan) “increased patient follow-up and improved recall of and adherence to ED discharge recommendations (5-21 year olds) (Zuckerbraun, 2014).”

Unmet Needs:

Poor psychosocial health was reported by a substantial portion in a study at one year post injury TBI may cause decades lasting vulnerability to psychiatric illness in some individuals. They were most susceptible to depression, delusional disorders and personality disturbances. This study highlights the importance of psychiatric follow up even decades (30 years) later (Kaponen, et al., 2002). Heinemann found unmet needs at 7 years. The most prevalent were improving memory and problem solving, increasing income and improving job skills (Heinemann, et al., 2002).

[Also see the Updated Mild Traumatic Brain Injury Guideline for Adults in this toolkit.](#)

Model of 6 types of concussion and active treatments (pediatric and adult):

There is now a great body of evidence supporting the 6 types of concussion and the active treatments for each type. A good resource to start with is *Concussion: A Clinical Profile Approach to Assessment and Treatment* by Kontos and Collins (2018) and *A comprehensive, targeted approach to the clinical care of athletes following sport-related concussion* (Collins, et al., 2013).

References

- Anderson, V. A., Catroppa, C., Dudgeon, P., Morse, S. A., Haritou, F., & Rosenfeld, J. V. (2006). Understanding predictors of functional recovery and outcome 30 months following early childhood head injury. *Neuropsychology*, 20(1), 42-57. doi:10.1037/0894-4105.20.1.42
- Anderson, V., Godfrey, C., Rosenfeld, J.V., & Catroppa, C., Predictors of Cognitive Function and Recovery 10 Years After Traumatic Brain Injury in Young Children. (2012). *Pediatrics*, 129(2). doi:10.1542/peds.2011-0311d
- Arbogast, K. B., Curry, A. E., Pfeiffer, M. R., Zonfrillo, M. R., Haarbauer-Krupa, J., Breiding, M. J., . . . Master, C. L. (2016). Point of Health Care Entry for Youth With Concussion Within a Large Pediatric Care Network. *JAMA Pediatrics*, 170(7). doi:10.1001/jamapediatrics.2016.0294
- Collins, M. W., Kontos, A. P., Reynolds, E., Murawski, C. D., & Fu, F. H. (2013). A comprehensive, targeted approach to the clinical care of athletes following sport-related concussion. *Knee Surgery, Sports Traumatology, Arthroscopy*, 22(2), 235-246. doi:10.1007/s00167-013-2791-6
- Corrigan, J. D., Wolfe, M., Mysiw, W. J., Jackson, R. D., & Bogner, J. A. (2001). Early identification of mild traumatic brain injury in female victims of domestic violence. *Clinical Journal of Womens Health*, 01(4), 184-190. doi:10.1053/cjwh.2001.27867

- Davies, S. C., Fox, E. E., Glang, A., et al. Traumatic Brain Injury and Teacher Training: A Gap in Educator Preparation. (2013). Counselor Education and Human Services Faculty Publications. 25. http://ecommons.udayton.edu/edc_fac_pub/25
- Ewing-Cobbs, L., Prasad, M. R., Kramer, L., Cox, C. S., Baumgartner, J., Fletcher, S., et al. (2006). Late intellectual and academic outcomes following traumatic brain injury sustained during early childhood. *Journal of Neurosurgery: Pediatrics*, 105(4), 287-296. doi:10.3171/ped.2006.105.4.287
- Farmer, J. E., & Johnson-Gerard, M. (1997). Misconceptions about traumatic brain injury among educators and rehabilitation staff: A comparative study. *Rehabilitation Psychology*, 42(4), 273-286. doi:10.1037//0090-5550.42.4.273
- Farrer, T. J., & Hedges, D. W. (2011). Prevalence of traumatic brain injury in incarcerated groups compared to the general population: A meta-analysis. *Progress in Neuro-Psychopharmacology and Biological Psychiatry*, 35(2), 390-394. doi:10.1016/j.pnpbp.2011.01.007
- Haarbauer-Krupa, J., King, T. Z., Wise, J., Gillam, S., Trapani, J., Weissman, B., & Depompei, R. (2019). Early Elementary School Outcome in Children With a History of Traumatic Brain Injury Before Age 6 Years. *Journal of Head Trauma Rehabilitation*, 34(2), 111-121. doi:10.1097/htr.000000000000041
- Haarbauer-Krupa, J., Lee, A. H., Bitsko, R. H., Zhang, X., & Kresnow-Sedacca, M. (2018). Prevalence of Parent-Reported Traumatic Brain Injury in Children and Associated Health Conditions. *JAMA Pediatrics*, 172(11), 1078. doi:10.1001/jamapediatrics.2018.2740
- Haarbauer-Krupa, J., Lundine, J. P., Depompei, R., & King, T. Z. (2018). Rehabilitation and school services following traumatic brain injury in young children. *NeuroRehabilitation*, 42(3), 259-267. doi:10.3233/nre-172410
- Hawthorne G, Gruen RL, Kaye AH. Traumatic brain injury and long-term quality of life: findings from an Australian study. *J Neurotrauma*. 2009;26:1623–33. doi: 10.1089/neu.2008.0735
- Heinemann, A. W., Sokol, K., Garvin, L., & Bode, R. K. (2002). Measuring unmet needs and services among persons with traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 83(8), 1052-1059. doi:10.1053/apmr.2002.3428
- Im, B., Hada, E., Smith, M., & Gertisch, H. (2014). The Relationship between TBI and incarceration rates. *Spotlight on Disability Newsletter*, Dec 2014 retrieved from <https://www.apa.org/pi/disability/resources/publications/newsletter/2014/12/incarceration>.
- Jones, S., Davis, N., & Tyson, S. F. (2017). A scoping review of the needs of children and other family members after a child's traumatic injury. *Clinical Rehabilitation*, 32(4), 501-511. doi:10.1177/0269215517736672
- Kaponen, S., Taiminen, T., Portin, R., et al. (2002). Axis I and II psychiatric disorders after traumatic brain injury a 30 year follow-up study. *Am J Psychiatry*, Aug; 159(8): 1315-21.
- Kontos, A. P., & Collins, M. W. (2018). *Concussion: A clinical profile approach to assessment and treatment*. Washington, DC: American Psychological Association.
- Kreutzer, J. S., Witol, A. D., & Marwitz, J. H. (1996). Alcohol and Drug Use Among Young Persons with Traumatic Brain Injury. *Journal of Learning Disabilities*, 29(6), 643-651. doi:10.1177/002221949602900608
- Lumba-Brown, A., Yeates, K.O., Sarmiento, K., et al. Centers for Disease Control and Prevention guideline on the diagnosis and management of mild traumatic brain injury among children [published online September 4, 2018]. *JAMA Pediatr*. doi:10.1001/jamapediatrics.2018.2853
- Mccarthy, M. L., Dikmen, S. S., Langlois, J. A., Selassie, A. W., Gu, J. K., & Horner, M. D. (2006). Self-Reported Psychosocial Health Among Adults With Traumatic Brain Injury. *Archives of Physical Medicine and Rehabilitation*, 87(7), 953-961. doi:10.1016/j.apmr.2006.03.007
- Morton, M. V., & Wehman, P. (1995). Psychosocial and emotional sequelae of individuals with traumatic brain injury: A literature review and recommendations. *Brain Injury*, 9(1), 81-92. doi:10.3109/02699059509004574
- Niedzwecki, C. M., Rogers, A. T., & Fallat, M. E. (2018). Using Rehabilitation along the Pediatric Trauma Continuum as a Strategy to Define Outcomes in Traumatic Brain Injury. *Clinical Pediatric Emergency Medicine*, 19(3), 260-271. doi:10.1016/j.cpem.2018.08.005

- Romero-Martinez, A., Moya-Albiol, L., Neuropsychology of perpetrators of domestic violence: the role of traumatic brain injury and alcohol abuse and/or dependence. (2013). *Revista de Neurologica*, Dec; 57(11): 515-522.
- Schwartz, L. (2003). Long-Term Behavior Problems Following Pediatric Traumatic Brain Injury: Prevalence, Predictors, and Correlates. *Journal of Pediatric Psychology*, 28(4), 251-263. doi:10.1093/jpepsy/jsg013
- Seabury, S.A., Gaudette, E., Goldman, A. J., et al. (2018). Assessment of Follow-up Care After Emergency Department Presentation for Mild Traumatic Brain Injury and Concussion: Result from the TRACK-TBI Study. *JAMA Network Open*. 208;1(1) doi:10.1001/jamanetworkopen.2018.0210
- Shiroma, E. J., Ferguson, P. L., & Pickelsimer, E. E. (2012). Prevalence of Traumatic Brain Injury in an Offender Population. *Journal of Head Trauma Rehabilitation*, 27(3). doi:10.1097/htr.0b013e3182571c14
- Slomine, B. S., McCarthy, M.L., Ding, R., et al. (2006). Health Care Utilization and Needs After Pediatric Traumatic Brain Injury. *Pediatrics*, 117(4). doi:10.1542/peds.2005-1892
- Suskauer, S. J., Rane, S., Reesman, J., & Slomine, B. S. (2018). Caregiver-report of symptoms following traumatic brain injury in a small clinical sample of preschool-aged children. *Journal of Pediatric Rehabilitation Medicine*, 11(1), 7-14. doi:10.3233/prm-160424
- Taylor, H. G., Swartwout, M. D., Yeates, K. O., Walz, N. C., Stancin, T., & Wade, S. L. (2008). Traumatic brain injury in young children: Postacute effects on cognitive and school readiness skills. *Journal of the International Neuropsychological Society*, 14(5), 734-745. doi:10.1017/s1355617708081150
- Taylor, H.G., Orchinik, L.J., Minich, N., et al. (2015). Symptoms of Persistent Behavior Problems in Children with Mild Traumatic Brain Injury. *J Head Trauma Rehabil*. Sep-Oct;30(5):302-10. doi:10.1097/HTR.000000000000106
- Taylor, H.G., Yeates, K. O., Wade, S.L., et al. (2002). A prospective study of short- and long-term outcomes after traumatic brain injury in children: Behavior and achievement. *Neuropsychology*, 16(1) 15-27.
- Todis, B., & Glang, A. (2008). Redefining Success. *Journal of Head Trauma Rehabilitation*, 23(4), 252-263. doi:10.1097/01.htr.0000327257.84622.bc
- Todis, B., Glang, A., Bullis, M., Ettel, D., & Hood, D. (2011). Longitudinal Investigation of the Post-High School Transition Experiences of Adolescents With Traumatic Brain Injury. *Journal of Head Trauma Rehabilitation*, 26(2), 138-149. doi:10.1097/htr.0b013e3181e5a87a
- Updated Mild Traumatic Brain Injury Guideline for Adults, retrieved from https://www.cdc.gov/traumaticbraininjury/mtbi_guideline.html
- Wagner, M., Newman, L., Cameto, R., Levine, P., and Garza, N. (2006). An Overview of Findings From Wave 2 of the National Longitudinal Transition Study-2 (NLT2). (NCSE 2006-3004). Menlo Park, CA: SRI International.
- Williams, W. H., Mewse, A. J., Tonks, J., Mills, S., Burgess, C. N., & Cordan, G. (2010). Traumatic brain injury in a prison population: Prevalence and risk for re-offending. *Brain Injury*, 24(10), 1184-1188. doi:10.3109/02699052.2010.495697
- Zgaljardic DJ, Seale GS, Schaefer LA, Temple RO, Foreman J, Elliott TR. Psychiatric disease and post-acute traumatic brain injury. *J Neurotrauma*. 2015;32:1911–25. doi: 10.1089/neu.2014.3569
- Zuckerbraun NS, Atabaki,S, Collins, MW, Thomas D, Gioia GA. Use of modified acute concussion evaluation tools in the emergency department. *Pediatrics*, 133(4). doi: 10.1542/peds.2013-2600d



www.tndisability.org/brain



Brain Links is supported by the Administration for Community Living (ACL) of the U.S. Department of Health and Human Services under Grant No. 90TBSG0024-01-00 and in part by the TN Department of Health, Traumatic Brain Injury Program.

