

# Traumatic Brain Injury In the District: The Ignored Injury

*A Paper Examining the Prevalence of TBI in the District and the Need for Services.*

## *Acknowledgments*

The TBI Work Group in Washington, D.C., acknowledges the authors of this report:

- Amy Bukowski, LICSW, ACT Clinical Supervisor, Community Connections, Inc.
- David Freeman, Psy. D., Chief Clinical Officer, Community Connections, Inc.
- Faiza Majeed, Esq., Disability Rights DC
- Jennifer “Niki” Novak, LMFT, LPC, Therapist at Pathways to Housing DC
- Paul Rubenstein, MSW, Resilience Strategies, Educational and Therapeutic Coaching
- Celeste Valente, MSW, LICSW, Advocate, Disability Rights DC

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- Penny L. Wolfe, Ph.D., ABPP, Neuropsychologist, Brain Injury Services, Medstar National Rehabilitation Hospital

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## *About the DC TBI Work Group*

In response to concerns about the lack of targeted community-based services available to residents with Traumatic Brain Injury (TBI), a number of advocates and service providers joined together to form the TBI Work Group in Washington, D.C, in 2013. The TBI Work Group has educated itself about the incidence and impact of TBI, visited TBI providers in other jurisdictions, shared knowledge with others in D.C. through trainings and advocacy, and sought funding to address TBI in collaboration with the D.C. Department of Behavioral Health, D.C. Department of Health, and federal agencies. After forming the TBI Work Group, members recognized that successful advocacy would depend on current data about the incidence of TBI in

D.C. In April and May 2016, the TBI Work Group conducted a survey on the incidence of TBI among adult consumers of behavioral health services in D.C. The TBI Work Group focused on the behavioral health population because of its exceptional vulnerability. This paper discusses the findings of the TBI Work Group survey and offers recommendations for the D.C. government to provide community-based services to D.C. residents with TBI. We recognize that a comprehensive plan to address the needs of people with TBI in D.C. requires concrete support from TBI experts and coordination of local funding streams and services. Staff from the following organizations has participated in the Work Group at various points since 2013: Community Connections, Department of Behavioral Health, Disability Rights DC at University Legal Services, Long-Term Care Ombudsman Services, Medstar National Rehabilitation Hospital, Public Defender Services, and Saint Elizabeth's Hospital.

## **Table of Contents**

<i>Acknowledgments</i> .....	2
<i>About the DC TBI Work Group</i> .....	2
<b>Executive Summary</b> .....	<b>5</b>
Recommendations .....	6
<b>Introduction and Overview</b> .....	<b>7</b>
<b>Clinical Vignette</b> .....	<b>10</b>
<b>The TBI Work Group Survey</b> .....	<b>11</b>
<b>Problems Associated with TBI</b> .....	<b>15</b>
<b>Clinical and Practical Accommodations</b> .....	<b>17</b>
Accommodations under the Americans with Disabilities Act .....	19
<b>Model Initiatives</b> .....	<b>20</b>
<i>Cognitive Rehabilitation and Day Activities or Treatment</i> .....	20
Case Management Targeted for TBI.....	21
<i>Residential Programs</i> .....	22
<i>Assessments and Accommodations</i> .....	23
<i>Funding Mechanisms</i> .....	23
<b>The Cost of Doing Nothing</b> .....	<b>25</b>
<b>Conclusion</b> .....	<b>26</b>

## **Executive Summary**

In 2016, 159 behavioral health services consumers in D.C. were surveyed by the TBI Work Group to collect data on the incidence of TBI. We chose to survey behavioral health consumers because of the prevalence of TBI within this population. Our survey found that approximately 50% of the adult behavioral health population surveyed has a history of TBI, though almost none had been diagnosed with that disorder. This rate of incidence suggests that TBI qualifies as a frequent co-occurring disorder. People with TBI might already receive community-based behavioral health services for a co-occurring mental illness, but not for TBI. Unfortunately, behavioral health providers do not screen, identify, or treat the symptoms of TBI because TBI is not an official billable diagnosis within D.C.'s behavioral health system and there is no system in place to train mental health providers. Community-based behavioral health providers in the D.C. cannot receive payment for services provided to treat the symptoms of TBI, whether it is a stand-alone diagnosis or a co-occurring disorder. Therefore, TBI is often not diagnosed or treated.

The lack of specific and targeted services for individuals with TBI comes at great human, societal, and fiscal cost: D.C. residents with TBI cycle between acute-psychiatric hospitals, are admitted to nursing facilities or psychiatric institutions that cannot properly address their needs, and are at great risk for homelessness and incarceration. It is time for the D.C. government to recognize that residents with TBI have little to no options for community-based treatment designed to meet their specific needs, and D.C. should develop community-based services for people with TBI. This paper is intended to prompt discussion and action among advocates,

service providers in the system of care, and the executive and legislative branches of government. By accepting these concrete recommendations, D.C. can begin to provide services for residents with TBI that would allow them to participate fully in society, to successfully live in the community, and to attain economic self-sufficiency:

*Recommendations*

- 1. Routine screening for TBI in multiple settings is critical, can improve treatment outcomes and should be available to all in need;**
- 2. Service providers at intake sites working in health and mental health, addressing the needs of the vulnerable people they serve should be trained in identification of TBI and the delivery of essential supportive accommodations;**
- 3. To accomplish these goals, it is essential to develop a funding strategy to support the following services: case management, day treatment, residential services, specialized behavioral health services as well as generally helping D.C. residents with TBI.**
- 4. D.C. should establish a commission to develop and establish community-based TBI services for adults and children in D.C. and monitor the implementation of TBI services in D.C.**

## Introduction and Overview

Every year, an estimated 1.7 million people sustain TBIs<sup>1</sup> in the United States.<sup>2</sup> It has been estimated that 3.2 million to 5.3 million Americans live with TBI-related disabilities.<sup>3</sup> TBI is a common co-occurring disorder<sup>4</sup> amongst people who are diagnosed with a major mental illness and who have a history of substance misuse, homelessness, and criminal justice involvement. A 2016 TBI screening conducted by the TBI Work Group found that approximately 50% of the 159 adult clients of behavioral health services surveyed had a history of TBI.<sup>5</sup> Forty three percent of those surveyed sustained their first TBI before they were 15.<sup>6</sup> TBI in adults is associated with increased risk for substance use, major depression, anxiety, unemployment, and divorce.<sup>7</sup> Individuals with TBI are four times more likely to attempt suicide

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<sup>1</sup> According to the Centers for Disease Control and Prevention “[a] TBI is caused by a bump, blow or jolt to the head or a penetrating head injury that disrupts the normal function of the brain. Not all blows or jolts to the head result in a TBI. The severity of a TBI may range from “mild,” i.e., a brief change in mental status or consciousness to “severe,” i.e., an extended period of unconsciousness or amnesia after the injury.” *Basic Information about Traumatic Brain Injury and Concussion*, Centers for Disease Control and Prevention, <https://www.cdc.gov/traumaticbraininjury/basics.html> (last visited June 7, 2017).

<sup>2</sup> Centers for Disease Control and Prevention, U.S. Department of Health and Human Services, *Get the Stats on Traumatic Brain Injury in the United States*, [http://www.ncdsv.org/images/CDC\\_GetStatsTBIintheUS.pdf](http://www.ncdsv.org/images/CDC_GetStatsTBIintheUS.pdf).

<sup>3</sup>Centers for Disease Control and Prevention & National Center for Injury Prevention and Control, Div. of Unintentional Injury Prevention, Report to Congress on Traumatic Brain Injury in the United States: Epidemiology and Rehabilitation (2015), [https://www.cdc.gov/traumaticbraininjury/pdf/tbi\\_report\\_to\\_congress\\_epi\\_and\\_rehab-a.pdf](https://www.cdc.gov/traumaticbraininjury/pdf/tbi_report_to_congress_epi_and_rehab-a.pdf).

<sup>4</sup> Comm. on Cognitive Rehab. Therapy for Traumatic Brain Injury, *Cognitive Rehabilitation Therapy for Traumatic Brain Injury: Evaluating the Evidence* 61-62 (Rebecca Koehler et al eds., 2011).

<sup>5</sup> TBI Work Group, Survey of TBI Within Four Core Service Agencies (May 2016) (unpublished raw data).

<sup>6</sup> *Id.*

<sup>7</sup> Suzanne Polinder et al., *Health-Related Quality of Life after TBI: A Systematic Review of Study Design, Instruments, Measurement Properties, and Outcome*, 13 Population Health Metrics 1 (2015).

than the general population.<sup>8</sup> Individuals diagnosed with TBI, mental illness, and substance abuse are 21 times more likely to attempt suicide.<sup>9</sup> These figures demonstrate the severe impact of TBI and co-occurring disorders.

D.C. residents with TBI have unmet services needs and lack appropriate care because there are no targeted or specialized community-based services designed to meet their specific conditions. Without necessary accommodations, persons with TBI who do not receive appropriate care are at significant risk for homelessness, incarceration, and institutionalization in psychiatric institutions and nursing facilities.<sup>10</sup> National statistics show that 50 to 80% of homeless individuals have sustained at least one brain injury prior to homelessness.<sup>11,12</sup> TBI in the prison population is estimated to range from 42 to 87%, with most brain injuries occurring before criminal behavior.<sup>13,14</sup> The incidence of TBI in jail and prison populations is especially relevant given the criminalization of mental illness; meeting the needs of persons with TBI could

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<sup>8</sup> Grahame Simpson & Robyn Tate, *Suicidality After Traumatic Brain Injury: Demographic, Injury, and Clinical Correlates*, 32 *Psychol. Med.* 687, 688 (2002).

<sup>9</sup> Marcelo Schwarzbald et al., *Psychiatric Disorders and Traumatic Brain Injury*, 4 *Neuropsychiatric Disease and Treatment* 797 (2008).

<sup>10</sup> Christina Dillahunt-Aspillaga et al., *Predictors of Behavioural Health Service Use and Associated Expenditures: Individuals with TBI in Pinellas County*, 29 *Brain Injury* 644 (2015).

<sup>11</sup> Jennifer L. Highley, Nat'l Health Care for the Homeless Council, *Traumatic Brain Injury Among Homeless Persons: Etiology, Prevalence, and Severity* (Brenda J. Proffit, ed., 2008), [http://www.nhchc.org/wp-content/uploads/2011/12/TBIAmongHomelessPersons\\_2008.pdf](http://www.nhchc.org/wp-content/uploads/2011/12/TBIAmongHomelessPersons_2008.pdf).

<sup>12</sup> Jane Topolovec-Vranic et al., *Traumatic Brain Injury Among People Who Are Homeless: A Systematic Review*, 12 *BMC Public Health* (2012).

<sup>13</sup> C.S. Allely, *Prevalence and Assessment of Traumatic Brain Injury in Prison Inmates: A Systematic PRISMA Review*, 30 *Brain Injury* 1161 (2016).

<sup>14</sup> A. Colantonio et al., *Traumatic Brain Injury and Early Life Experiences Among Men and Women in a Prison Population*, 20 *J. of Correctional Health Care* 271 (2014).

alleviate much of the strain on the criminal justice system and destigmatize treatable conditions. TBI is also prevalent among those hospitalized for mental health disorders; with the head injury most often occurring prior to onset of psychiatric symptoms.<sup>15</sup> Additionally, persons with TBI experience significant barriers to accessing appropriate care and support in their community, including racial inequalities in access to care (TBI is over represented in African-American and Hispanic populations); severe limitations in practical resources like adequate housing and transportation; limitations in services including supported employment and case management; and restrictive, inflexible public policy that creates barriers to diagnosis and treatment of TBI.<sup>16,17</sup>

The symptoms and functional deficits of TBI can serve as major barriers to successful community integration, especially when they serve to intensify symptoms of behavioral health disorders. To further complicate matters, many of the symptoms and functional deficits associated with TBI both overlap with, mask and are masked by those of the major mental illnesses. As co-occurring disorders, TBI, major mental illness, violent victimization, institutionalization and substance addiction, can be exceptionally difficult to assess, differentially diagnose and treat. At times, when a person with TBI has a co-occurring mental illness, symptoms related to the TBI can be attributed to the mental illness. In these cases, the person with a TBI receives misguided services from providers that have not been appropriately trained

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<sup>15</sup> Dillahunt-Aspillaga et al., *supra*.

<sup>16</sup> Kelli Williams Gary et al., *Do Racial/Ethnic Differences Exist in Post-Injury Outcomes After TBI? A Comprehensive Review of the Literature*, 23 *Brain Injury* 775 (2009).

<sup>17</sup> Polinder et al., *supra*.

to recognize and treat the TBI symptoms. The need for training is highlighted by these clinical complexities.

### *A Note about Children with TBI*

Although the TBI Work Group survey focused on adults, national statistics indicate that children are more likely to sustain a TBI, and that young children 0 to 4 years old have the highest rate of TBI-related emergency department visits.<sup>18</sup> Furthermore, persons exposed to head injury between the age of 11 and 15 have a higher correlation of mental illness.<sup>19</sup> Clearly, there is a need to study TBI amongst children and older adolescents in D.C. further.

### **Clinical Vignette**

Mr. C (identity fully disguised), a 35-year-old, homeless male, was discharged from the psychiatric emergency room and referred to a community-based crisis house for stabilization of symptoms associated with a major mental illness and addiction, including paranoia, aggressive behavior, disorganization, impulsivity, and “treatment non-compliance”. Mr. C had been admitted to the ER at least three other times in the previous three months. Within an hour of admission to the new program, Mr. C reported he was going to “kirk out.” By this time, however,

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<sup>18</sup> Mark Faul et al., Ctrs. for Disease Control and Prevention & Nat'l Ctr. for Injury Prevention and Control, *Traumatic Brain Injury in the United States: Emergency Department Visits, Hospitalizations and Deaths 2002–2006* (2010), [https://www.cdc.gov/traumaticbraininjury/pdf/blue\\_book.pdf](https://www.cdc.gov/traumaticbraininjury/pdf/blue_book.pdf).

<sup>19</sup> Sonja Orlovska et al., *Head Injury as Risk Factor for Psychiatric Disorders: A Nationwide Register-Based Follow-Up Study of 113,906 Persons With Head Injury*, 171 *Am. J. of Psychiatry* 463 (2014).

staff had already become fearful of Mr. C’s “erratic and impulsive” behavior and had called the Mobile Crisis<sup>19</sup> team for assistance with a re-hospitalization. After Mobile Crisis was already dispatched, agency staff called back to say Mr. C. seemed calm and was taking a walk with a counselor who happened to have training in identifying and treating TBI.

Like so many individuals who have a major mental illness and who are homeless, Mr. C has a history of TBI, an important factor in understanding his poor outcomes. He lacks the tools, social supports, and resources to manage the symptoms of his TBI, and providers lack the targeted knowledge and skills to help him develop those tools. Most importantly, Mr. C demonstrates the practical value of providing D.C. residents with TBI services optimized to meet their specific needs. While Mr. C was able to de-escalate so that he could work with a counselor, a great deal of stress, in addition to resources, could have been saved had there been a system in place designed to recognize TBI and address its specific needs.

### **The TBI Work Group Survey**

To quantify the extent of our concerns, the TBI Work Group successfully collaborated with four community-based behavioral health providers in D.C. and gathered data on the incidence and severity of TBI in their client populations in April and May 2016. Findings are noteworthy on several fronts. From a clinical perspective, the TBI Work Group found a history

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<sup>20</sup> Mobile Crisis is a service offered by the Department of Behavioral Health (DBH). Mobile Crisis teams respond to adults in the D.C. who are experiencing psychiatric crisis and who are unable or unwilling to receive mental health services. Mobile Crisis provides crisis stabilization, assessments for hospitalization, and linkages to other services. *See* Emergency Psychiatric Services, Department of Behavioral Health, <https://dbh.dc.gov/service/emergency-psychiatric-services> (last visited July 5, 2017).

of TBI in approximately 50% of the client population; the severity of injury ranges widely, but includes some severe injuries; most injuries were not addressed at the time of occurrence; and current behavioral health treatment plans do not specifically address the potential sequelae of the injuries.<sup>20</sup> From an administrative perspective, the Work Group found that most providers are hesitant to focus on TBI when they do not receive reimbursement for the work even when TBI is identified as an important factor in the etiology of illness.

The four Core Service Agencies (CSA) who participated in the survey were Community Connections (94 surveys), Green Door (31 surveys), Pathways to Housing (8 surveys) and Anchor Mental Health (26 surveys). Surveys were completed at the time of intake.

<b>Agency</b>	<b># of Surveys Completed</b>	<b>Positive for TBI on Initial Screen</b>	<b>Percentage Positive for TBI on Initial Screen</b>
Community Connections, Inc.	94	45	48%
Green Door Behavioral Health	31	20	65%
Anchor Mental Health	26	9	35%
Pathways to Housing	8	2	25%
<b>Totals</b>	<b>159</b>	<b>76</b>	<b>48%</b>

Chart of Agency Surveys

The CSAs used the Ohio State University Traumatic Brain Injury Identification Method (OSU TBI-ID) developed by TBI expert John Corrigan, PhD and his colleagues at Ohio State

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<sup>21</sup>TBI Work Group, Survey of TBI Within Four Core Service Agencies (May 2016) (unpublished raw data).

University.<sup>21</sup> The OSU TBI-ID is a standardized procedure for eliciting a person's lifetime history of TBI through a short structured interview.<sup>22</sup> The OSU TBI-ID is conducted in three steps: the first step probes for history of TBI in a series of five questions; the second step inquiries about loss of consciousness if there was a TBI; the third step explores the history of multiple, mild TBIs.

The TBI screeners received training in the use of the OSU TBI-ID by staff from the Medstar National Rehabilitation Hospital, St. Elizabeth's Hospital, Community Connections, Green Door, and Educational and Therapeutic Coaching. Trained screeners were licensed professionals. In addition to yielding some basic quantitative information about the incidence of TBI, some qualitative information is also gathered in the OSU TBI-ID. Screeners found that TBIs in the screened population were the result of car accidents, drunken falls, sports injuries, family violence, child abuse, and community violence. In the most extreme cases, individuals experienced a coma for several months.

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<sup>22</sup>See *OSU TBI-ID*, OHIO VALLEY CENTER FOR BRAIN INJURY PREVENTION AND REHABILITATION, <http://ohiovalley.org/tbi-id-method/> (last visited May 23, 2017).

<sup>23</sup> *Id.*

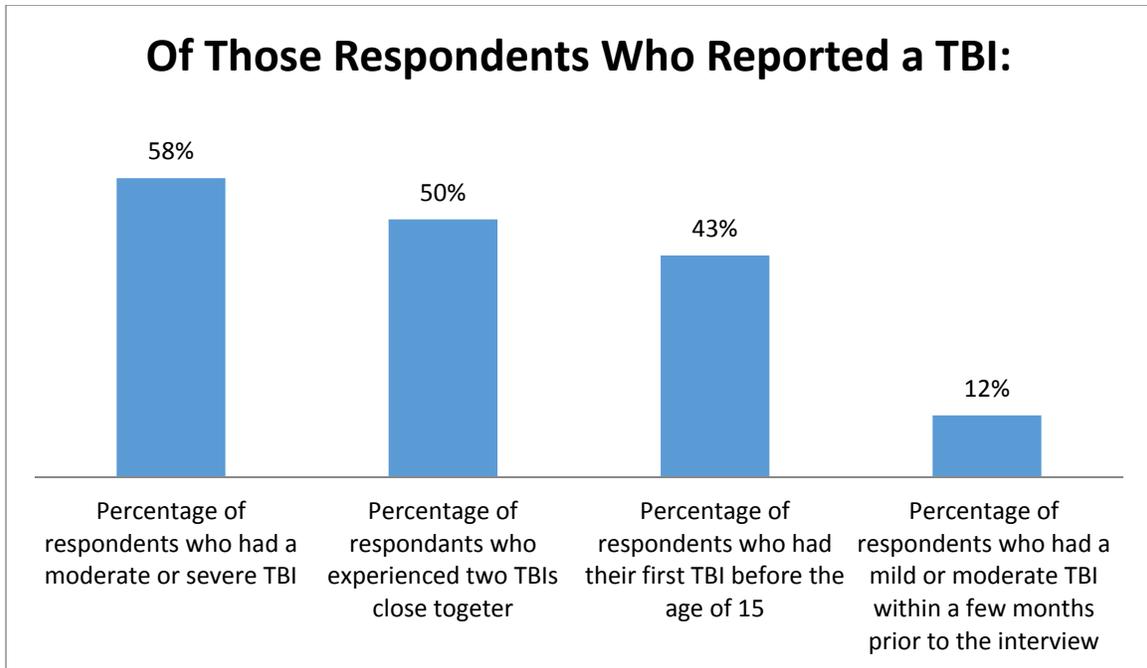


Chart of Respondents

Overall, the TBI Work Group found that clients were eager to discuss their history of TBI. In general, the more specific the question, the more people were willing to describe their experience. Mr. C, for example, readily discussed his history of TBI with a TBI-informed staff person who helped defuse the crisis. Once the staff person expressed interest in Mr. C’s history, Mr. C was more able to talk about needed accommodations and problem-solving strategies. Like most of the consumers the TBI Work Group interviewed, Mr. C was ready and eager to develop a more thorough and sophisticated understanding of the problems affecting his ability to live a satisfying and independent life.

The findings in this two-month period of review are consistent with an earlier study at Community Connections which identified TBI as an important risk factor in responsiveness to

treatment.<sup>23</sup> In that Community Connections study, the more severe and frequent the TBI, the less likely that “services as usual” for co-occurring disorders of addiction and mental illness were effective.<sup>24</sup>

### **Problems Associated with TBI**

Persons with TBI experience difficulties with self-regulation and executive functioning and need specific associated accommodations.

Self-regulation refers to a person’s ability to manage behavior associated with stress and anxiety; recognize stress in themselves and others; develop coping strategies to reduce (and anticipate) stress, and develop social and emotional resiliency.<sup>25</sup> For a person with TBI, problems with self-regulation might entail difficulty waiting or taking turns; difficulty calming down; or feeling overwhelmed in new places or by loud noises or in crowds.

Executive functioning refers to higher-order brain functions associated with setting goals, organizing, remembering, following directions, and focusing attention.<sup>26</sup> People with TBI often have cognitive impairments that limit these executive functioning skills; they can become easily confused or forgetful. Other people with TBI may have difficulty learning new information, filling out forms, using public transportation. Some have difficulty problem-solving, and others have problems with judgment and decision-making. After experiencing a TBI, people may have

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<sup>24</sup> Community Connections study (Fallot, personal communication, 2011)

<sup>25</sup> Community Connections study (Fallot, personal communication, 2011)

<sup>26</sup> See Mary Kennedy & Carl A. Coelho, *Self-Regulation after Traumatic Brain Injury: A Framework for Intervention of Memory and Problem Solving*, 26 Seminar in Speech and Language 242 (2005).

<sup>27</sup> *Id.*

trouble keeping track of time, making plans, making sure to complete plans or assignments, multitasking, applying previously learned information to solve problems, analyzing ideas, and looking for help or more information when needed. To the untrained eye, problems with executive functioning can look like lack of motivation, laziness, disregard for others, and a reluctance to engage in social activities. This untrained judgment can lead to unnecessary stigmatization and poor treatment.

Mr. C demonstrates how providers' misunderstanding of these problems can lead to chronic stress and mismanagement. Instead of receiving treatment for his TBI, Mr. C was referred to an agency that provided counseling for alcohol abuse, given a prescription for anti-depressants, and encouraged to obtain a GED. His symptoms were mischaracterized and misunderstood by providers who tried to fit his presentation into a behavioral health paradigm; not trained in recognizing the impact of TBI, they could not properly diagnose and plan for treatment. Similarly, Mr. C. often felt mismatched with the behavioral health providers he contacted. He described difficulty filling out forms which were designed to identify symptoms of mental illness and addiction, feeling that his experience was not adequately captured in these traditional forms. Further, he was unsure of how to respond to staff inquiries and judgments. For example, he was sometimes told he was "drunk," or "crazy," which intensified his sense of anxiety and alienation from service providers. The accommodations recommended by the TBI Work Group would help Mr. C and others like him to have a more successful community adjustment.

## Clinical and Practical Accommodations

To accommodate is to “provide services in a manner that takes into consideration the special needs of an individual.”<sup>27</sup> Staff in all settings that address the needs of vulnerable people should be trained in identification of TBI and the delivery of essential supportive accommodations. Currently, there is no clear designation for services for individuals with TBIs in D.C.’s behavioral health system. This makes it impossible for people with TBI to access appropriate services. D.C. needs to improve access to care to ensure that people who sustain TBI have a variety of services and supports available to them at varying intensities.

Since symptoms of TBI often overlap with symptoms associated with persistent mental illnesses, clinicians are often lulled into a sense of complacency, believing they understand the clinical presentation more fully than they actually do. The most effective way to help people with TBI learn new and compensatory strategies is to first properly diagnose TBI and recognize it as a complex mix of cognitive, social, emotional, and communication challenges.

For illustrative purposes, the TBI Work Group has identified four major neurocognitive functions that are generally affected by deficits in executive functioning and which need accommodation: attention, processing, memory and decision making and planning.<sup>28</sup> The chart below offers examples of concrete steps to accommodate people with TBI so they can develop skills for their recovery.

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<sup>28</sup> *Accommodating the Symptoms of TBI*, THE OHIO VALLEY FOR BRAIN INJURY PREVENTION AND REHABILITATION, <http://ohiovalley.org/informationeducation/accommodatingtbi/> (last visited Mar. 29, 2018).

<sup>29</sup> *Cognitive Problems After Traumatic Brain Injury*, BRAINLINE, <https://www.brainline.org/article/cognitive-problems-after-traumatic-brain-injury> (last visited Mar. 29, 2018).

## Attention

- Break down information into manageable steps
- Offer demonstration or practice
- Use frequent, but compassionate redirection
- Keep instructions brief, simple, and to the point

## Processing

- Give extra time to process information
- Simplify: provide one idea or task at a time
- Provide an opportunity to ask that information be given more slowly

## Memory

- Reinforce communication with additional prompts and/or tools (such as a journal or calendar)
- Provide information in several different ways
- Use repetition, especially for new information

## Decision Making and Planning

- Create a short-term action plan
- Develop and maintain consistent routines throughout the day
- Ask the individual with a TBI how he or she is best able to learn and what has changed or is challenging for them

There are many potential cognitive, behavioral, and emotional sequelae of TBI. The four areas highlighted in the chart above are common interventions, but are only examples of the many potential activities and accommodations that could be implemented. If service providers are trained to be aware of the symptoms of TBI then they can successfully develop accommodations which address potential barriers to treatment success. Service providers can benefit from having more practical skills in their repertoire to provide concrete interventions to D.C. residents with TBI.

*Accommodations under the Americans with Disabilities Act*

The Americans with Disabilities Act of 1990 (ADA) requires our public behavioral health system and any future services for people with TBI to provide accommodations to people with TBI so they can participate in and benefit from programs.<sup>29</sup> The ADA requires that qualified individuals with a disability receive reasonable modifications and services free from discrimination based on their disability. A person has a disability under the ADA if they have physical or mental impairment that substantially limits one or more major life activities.<sup>30</sup> While the determination of whether someone has a disability under the ADA is specific to that individual and the symptoms of their TBI, the TBI Work Group's findings demonstrate that TBI and its sequelae frequently meets the definition of disability as defined under the ADA.

Title II of the ADA applies to local and state governments and requires that people with disabilities receive equal opportunities to access government services, programs, and activities.<sup>31</sup> Title III of the ADA applies to places of public accommodations, including social service centers and professional offices of health care providers, and requires that they reasonably modify policies, practices, or procedures to give people with disabilities an equal opportunity and access to services.<sup>32</sup> The cognitive, behavioral, and emotional manifestations of TBI present barriers for people with TBI to accessing services and participating in programs. The ADA requires that

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<sup>30</sup> See 42 USC § 12131; 28 CFR § 35.101..

<sup>31</sup> 42 USC § 12102 (1)(A)-(B).

<sup>32</sup> See 42 USC § 12131; 28 CFR § 35.101..

<sup>33</sup> See 42 USC § 12181.; 28 CFR § 36.101.

providers and programs reasonably modify their policies and practices to ensure that people with TBI have an equal opportunity to access services they provide.

**Model Initiatives**

Unlike Washington, D.C., other states have developed TBI service programs. Some states offer robust programs that provide services and supports, such as case management, cognitive rehabilitation, day services, and in-home residential services for individuals and family members. The TBI Work Group looked at services in Maryland, Virginia, Colorado, and Alaska to obtain information on what a functioning TBI service system should offer. Although, this is not an exhaustive list of TBI services offered in states around the country, the Work Group looked at these states because they illustrate different strategies to treating TBI in the community.

Cognitive Rehabilitation	Case Management	Residential Services	Screening & Accommodation
<ul style="list-style-type: none"> <li>• Colorado</li> <li>• Maryland (if in waiver)</li> <li>• Virginia</li> </ul>	<ul style="list-style-type: none"> <li>• Alaska</li> <li>• Colorado</li> <li>• Maryland (if in waiver)</li> <li>• Virginia</li> </ul>	<ul style="list-style-type: none"> <li>• Colorado</li> <li>• Maryland (if in waiver)</li> <li>• Virginia</li> </ul>	<ul style="list-style-type: none"> <li>• Alaska</li> <li>• Colorado</li> <li>• Maryland</li> <li>• Virginia</li> </ul>

Chart of State Services

*Cognitive Rehabilitation and Day Activities or Treatment*

Virginia, Colorado, and Maryland (for Medicaid waiver recipients) offer programs for individuals with TBI that specialize in cognitive rehabilitation. Moreover, day activities or treatment with different focuses (including Clubhouse programs) provide individualized skills training, cognitive rehabilitation, and work reentry. In Virginia, two Clubhouses offer vocational

and daily skills training. The Clubhouses provide skills development through training in technology and general work and life skills and by providing opportunities to manage the Clubhouse itself and participate in volunteer activities.<sup>33</sup> If D.C. funded a TBI program that provides TBI treatment and training during the day, Mr. C would have the opportunity to relearn life skills, such as how to interact appropriately in social settings, negotiate public transportation to get to medical appointments or how to cook a simple meal.

### *Case Management Targeted for TBI*

Case management functions provide supports to achieve the goals of a person-centered plan. Case management assists the consumer to address basic needs, such as keeping appointments, developing a therapy and medication schedule, and accessing public benefits. Maryland, Alaska, Virginia and Colorado offer case management for individuals who are diagnosed with a TBI. These states have realized that case management provides a building block for persons recovering from TBI or for persons who are living with the chronic effects of TBI.

The Colorado Brain Injury Alliance (BIAC) uses a problem-solving proactive approach to case management. “BIAC staff are the collaborators and creative problem-solvers, helping to find resources survivors need to become their own self-advocates.”<sup>34</sup> The BIAC provides case management services for youth and adults. These services are free to anyone with a brain injury

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<sup>34</sup> *ADAPT Programs and Activities*, BRAIN INJURY SERVICES, <http://braininjurysvcs.org/what-we-do/core-programs-services/adapt-clubhouse/activities/> (last visited June 9, 2017).

<sup>35</sup> *Case Management*, BRAIN INJURY ALLIANCE OF COLORADO, <https://biacolorado.org/case-management/> (last visited June 9, 2017).

living in Colorado. The model uses a team approach and incorporates a continuity of care philosophy from childhood to adulthood. The BIAC also plans to offer special support and consultation for school related issues for children/youth with TBI.<sup>35</sup> If Mr. C had access to TBI targeted case management, he might have avoided an ER admission, a visit to the psychiatric emergency room in D.C., and a stay at the crisis bed facility. Working with a case manager with clinically appropriate interventions and accommodations would have helped Mr. C connect to services and benefits, coordinate care, and manage activities in daily life.

### *Residential Programs*

Both Maryland and Colorado have a range of housing opportunities available to persons with TBI. Both states have developed a network of service providers who are capable of offering housing choices and trained staff for individuals who qualify for these services. In Maryland, housing services are available to those who qualify for the Maryland TBI Waiver. Colorado has a network of residential providers who provide choices, ranging from Supported Independent Living with trained staff to housing with progressively independent settings. In some cases, residential options provide drop-in supports as part of the residential services array. Access to housing would have helped Mr. C remain safe, organize his medications, and keep track of important paperwork, such as identification cards and bank statements.

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<sup>36</sup> *Id.*

### *Screening and Accommodations*

Maryland conducts screening for TBI as part of its healthcare assessments. Maryland screens for TBI in healthcare and behavioral health settings and includes questions from the OSU TBI-ID.<sup>36</sup> It is essential that D.C. create a system of TBI screening and provide accommodations at its medical and psychiatric intake sites, including hospital emergency departments, jails, drug treatment programs, in-patient psychiatric units, core service agencies, and the Comprehensive Psychiatric Emergency Program (CPEP). Clinical intake assessments are already conducted throughout the city and can incorporate an accurate assessment of the history of TBI for a person including the impact of TBI, symptoms, and needed accommodations. This would enable staff to recognize common symptoms of TBI and to incorporate accommodating strategies into their work. For someone such as Mr. C, this recognition could have avoided unnecessary crises. If D.C. had a network of TBI specific services, Mr. C could have been linked with a more optimized support network, instead of utilizing excessive resources aimed at meeting other less important needs.

### *Funding Mechanisms*

Alaska's approach to funding TBI services uses a simplified model. Instead of creating special funds to address treatment for people with TBI, it incorporates TBI services within the already existing state mental health agency. Alaska does this by focusing on the "CBEs": the Cognitive, Behavioral, and Emotional manifestations of a brain injury. Alaska treats CBE

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<sup>37</sup> E-mail from Stefani O'Dea, Director of Older Adults and Long Term Services and Supports in MD, (Dec. 2, 2016).

symptoms within the mental health system and adopted the federal definition of “Adults with a Serious Mental Illness.” As such, treatment can be billed to Medicaid or to other state mental health grants.<sup>37</sup>

Approximately half of all states make use of a Medicaid Home and Community-based Services Waiver to fund services for some individuals with a TBI diagnosis.<sup>38</sup> Alternatively, twenty-three (23) states have established trust funds dedicated to funding brain injury programs.<sup>39</sup> Many states have appropriations directed by their state legislature to support these programs.

There are pros and cons of these funding mechanisms. For example, a Home and Community-based Services Waiver can effectively fund an array of services for individuals with profound needs, oftentimes individuals who would otherwise be institutionalized. However, a waiver alone usually serves only a limited number of individuals due to strict admission criteria. For example, in Maryland there are more than 7000 Medicaid beneficiaries living with brain injuries, but the brain injury waiver only serves approximately 85 people.<sup>40</sup> Eligibility for the

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<sup>38</sup> Leonard Abel, Traumatic Brain Injuries and Mental Health- Is This Really Our Problem?, [http://dhss.alaska.gov/dbh/Documents/Resources/tbi\\_and\\_mental\\_health.pdf](http://dhss.alaska.gov/dbh/Documents/Resources/tbi_and_mental_health.pdf).

<sup>39</sup> Cynthia O'Donoghue et al., Va. Dep't for Aging and Rehab. Servs., Access to Neurobehavioral Services in Virginia (2016), <https://www.vadars.org/cbs/downloads/JMUNeurobehavioralSvcsReport-2016.pdf>.

<sup>40</sup> *Id.*

<sup>41</sup> E-mail from Stefani O'Dea, Director of Older Adults and Long Term Services and Supports in MD, (Dec. 2, 2016); The TBI Advisory Board Report, 2016, p. 11.

waiver is also limited to individuals transitioning out of state-operated chronic care facilities and psychiatric hospital settings.<sup>41</sup>

### **The Cost of Doing Nothing**

Mr. C demonstrates a series of problems that led to unnecessary costs. Had he received TBI- informed case management, housing, and vocational supports, he may have avoided monthly trips to the emergency room and his incarcerations. Nationally, direct medical costs and loss of productivity associated with TBI exceeds approximately \$76 billion annually.<sup>42</sup> Locally, the costs also add up quickly. The median length of stay of 74 days at Saint Elizabeth’s costs \$70, 596<sup>43</sup>, a night in jail in D.C. costs \$133 per day<sup>44</sup>, a night in a low barrier shelter cost \$30

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<sup>42</sup> *Traumatic Brain Injury*, Md. Dep’t of Health, <https://bha.health.maryland.gov/pages/Traumatic-Brain-Injury.aspx> (last visited March 29, 2018).

<sup>43</sup> *Severe TBI*, CENTERS FOR DISEASE CONTROL AND PREVENTION, <https://www.cdc.gov/traumaticbraininjury/severe.html> (last visited June 9, 2017).

<sup>44</sup> The daily cost per bed at Saint Elizabeths Hospital is estimated to be \$954. *See* Ctr. for Court Excellence, *Improving Mental Health Services and Outcomes for All: The D.C. Department of Behavioral Health and the Justice System*, at 50, [http://www.courtexcellence.org/uploads/publications/ODCA\\_Report\\_Audit\\_of\\_DBH\\_2.pdf](http://www.courtexcellence.org/uploads/publications/ODCA_Report_Audit_of_DBH_2.pdf) (last visited Mar. 29, 2018).

<sup>45</sup> Rachel Chason, *Doing Time Far From Home, D.C. Prisoners Face Extra Barriers to Rehabilitation*, WASH. POST, (Dec. 13, 2007), [https://www.washingtonpost.com/local/dc-politics/incarcerated-in-federal-prisons-far-from-home-dc-prisoners-face-extra-barriers-to-rehabilitation/2017/12/13/b57d42aa-ca5e-11e7-aa96-54417592cf72\\_story.html?utm\\_term=.7bdf164a1fbc](https://www.washingtonpost.com/local/dc-politics/incarcerated-in-federal-prisons-far-from-home-dc-prisoners-face-extra-barriers-to-rehabilitation/2017/12/13/b57d42aa-ca5e-11e7-aa96-54417592cf72_story.html?utm_term=.7bdf164a1fbc).

and \$11,015 annually<sup>45</sup>, and an emergency department visit can cost between \$861-\$1017.<sup>46</sup> Every time an individual with TBI is neglected, D.C. residents pay for it.

## Conclusion

Increasingly, TBI is recognized as a major public health issue. So, too is the failure to identify and provide appropriate services for individuals living with TBI. Rates of TBI are significantly higher among the homeless; those seeking mental health services; the incarcerated; survivors of domestic violence; those who struggle with addiction; and individuals in need of vocational rehabilitation.<sup>47</sup> TBI's impact affects every aspect of the individual's being, including the connection to oneself and to others.

In addition to presenting a significant burden for people with TBI and their families, traumatic brain injury results in high economic and social cost to communities and governments. Persons with TBI whose rehabilitative needs are unmet fail to reenter the workforce thus placing an additional burden on government. Likewise, persons whose needs are unmet because of misdiagnosis or lack of services are at even further at risk for lifetime dependence on government assistance.<sup>48</sup> It is time for D.C. to recognize the prevalence of TBI among D.C.

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46 D.C. Interagency Council on Homelessness, *Homeward DC 2015-2020*, 78, [https://ich.dc.gov/sites/default/files/dc/sites/ich/page\\_content/attachments/ICH-StratPlan2.9-Web.pdf](https://ich.dc.gov/sites/default/files/dc/sites/ich/page_content/attachments/ICH-StratPlan2.9-Web.pdf) (last visited Mar. 28, 2018).

47 The Advisory Bd. Co., *Uncovering the Health Care and Police Cost of Chronic Homelessness in the District*, [https://www.streetsensemedia.org/wp-content/uploads/2015/03/Uncovering-Cost-of-homelessness\\_DC\\_The-Advisory-Board-Company.pdf](https://www.streetsensemedia.org/wp-content/uploads/2015/03/Uncovering-Cost-of-homelessness_DC_The-Advisory-Board-Company.pdf) (last visited Mar. 29, 2018).

48 [Kristen Dams O'Connor et al.](#), *Screening for Traumatic Brain Injury: Findings and Public Health Implications*, 29 *J. of Head Trauma Rehab.*, 29, 479 (2014).

49 Craig M. Kabatchnick, *The TBI Impact: The Truth About Traumatic Brain Injuries and Their Indeterminate Effects on Elderly, Minority, and Female Veterans of All Wars*, 11 *Marquette Elder's Advisor* 81 (2009).

residents and to develop community-based services similar to other states in the U.S. to provide people with TBI with the supports necessary to participate fully in society and to attain economic self-sufficiency.