

**Findings from the District of Columbia
Traumatic Brain Injury
Needs and Resources Assessment of:**

**Homeless Adult Individuals
Homeless Shelter Providers
TBI Survivor and Family Focus Group
TBI Service Agency/Organizations**

August 2010

The TBI Implementation Grants Program with the DC Department of Health, Bureau for Cancer and Chronic Disease at (202) 442-5925; or the DC Brain Injury Association at (202) 659-8600.
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Executive Summary

A traumatic brain injury can occur when a person experiences blunt force or a penetrating injury to the head as can occur from a fall, motor vehicle crash, or assault. Ensuring that appropriate services are provided for traumatic brain injury patients can be complicated for a number of reasons, and common co-factors such as homelessness, complicate care further.

The goal of the District of Columbia Traumatic Brain Injury (TBI) Implementation Project is to assess and mitigate the challenges faced by people living with TBI many of whom are also part of the District's homeless population or are women receiving services from domestic violence shelters. Homeless individuals are at ongoing risk for head injury and a number are believed to be veterans who may have sustained head injuries and/or post traumatic stress disorder (PTSD) from their military service.

The Traumatic Brain Injury Needs and Resources project among Homeless Adults and Homeless Providers in the District of Columbia began in May 2009 with a pilot study. Implementation of the full study was completed in February 2010. Additional project components to assess needs of non-homeless TBI survivors (Focus Group and survey of TBI Agencies/Organizations) were conducted in May-June, 2010. The four study components were designed to describe:

- 1) characteristics of TBI survivors, including military veterans
- 2) education and training needs
- 3) current health and behavioral issues
- 4) gaps in services and resources

Findings from Homeless Individual Surveys include:

- 199 homeless individuals participated in this survey;
- Nearly two-thirds (64.8%) homeless participants reported a history of head trauma.
- The demographic characteristics of homeless respondents reporting a history of head injury were the following:
 - At least half were 48 years of age or older;
 - 85.3% were African American, non-Hispanic;
 - 78.3% were Male;
 - 67.4% reported education levels of high school graduate/GED certificate or above;
 - Single, never married (72.9%);
 - 61.2% were parents with children age 1 to 12; about half (48.1%) reported having 1-3 children; none of the respondents indicated their child resided with them;
- Current length of time homeless in the District of Columbia ranged from 1 week to 39 years, average 3.4 years, with a median and mode of 1 year.
- Nearly one-fourth (21.8%) of male respondents reporting a head injury were veterans, having served in the US military or the Reserves.
- The three most frequently reported causes of head trauma reported by homeless adults in the District were fights or assaults (36.2%); falls (27.6%); and motor vehicle crashes (18.6%)

- Compared to respondents without a history of TBI, TBI respondents were significantly more likely to be current cigarette smokers ($X^2 = 15.398$; $p < .001$); to have ever been diagnosed with high blood pressure ($X^2 = 8.756$; $p = .003$); and to have ever been diagnosed with asthma ($X^2 = 6.906$; $p = .009$).
- Over half (57%) of current smokers indicated they wanted to stop smoking and/or that they wanted help to quit smoking;
- Of the 137 respondents completing this survey item, about one-third (35%) indicated current alcohol and/or drug use;
- The most frequently reported current ailments that respondents believed might be related to their past head injury included dislike of crowds (45%); sleep problems (42%); and headaches (38%).
- The most frequently reported sources of TBI information for respondents with a history of head injury were health care providers (36%); pamphlets/ brochures (26%); and case manager/counselors (26%). Most (83%) indicated they would like to know more about brain injury effects;
- The most frequently reported services and supports used by brain injured homeless adults included help from the church (38%); health and rehabilitation services (31%); and housing assistance (29%).
- The majority (85%) of homeless respondents with a history of head injury are unemployed; about half (47%) reported they currently are looking for employment.
- Employment barriers included transportation needs (50%) and job training needs (40%).

Findings from Homeless Service Providers Survey include:

- Twelve (12) homeless service providers responded to the survey;
- Homeless providers reported sheltering a range of 40-130 individuals on any given day or night, an average of 75 individuals. Of these, providers estimated that approximately 0-80% of these individuals could be TBI survivors;
- When asked if they or staff members had received any training and education on TBI or head injury, only one provider (8%) indicated training, and all (100%) indicated their belief that staff would benefit from TBI training;
- Homeless shelter providers reported their organization most frequently provides the following types of services/assistance: Housing assistance (75%); Employment assistance (75%); Transportation assistance (75%); and Money management services (67%);
- When asked which services and assistance they believed were most needed by homeless individuals with TBI, providers most frequently indicated the following: Individual counseling (75%); Mental health counseling (67%); Housing assistance (67%); Medical care (67%); GED/High school diploma (67%); Vocational training (58%); and Nutrition (58%);
- The following types of support groups/services were most frequently provided: Substance abuse groups (9/12); Social/Life skills (5/12); and Housing programs/support (5/12).

Focus Group Findings

- There were 18 participated in the focus group
- About two-thirds of the National Rehabilitation Hospital (NRH) focus group participants who completed the demographic sheets reported they were TBI survivors (67%);
- Most (67%) focus group members were female; the average age was 45.3 years, (though younger participants arrived near the end of the session and did not complete demographic sheets); and the majority (89%) of respondents were white;
- This group reported high levels of education—most (78%) were college graduates with degrees—BA (2); Master’s (3); and PhD (1);
- The majority (56%) of respondents were single, never married;
- The most frequently reported type of health care coverage for the TBI survivor was public insurance such as the DC Healthcare Alliance, Medicaid, and Medicare (67%);
- Results of the focus group analysis identified four main TBI themes: the importance of social networks/informal systems of support; system navigation issues; employment-related concerns; and lack of training/awareness among providers;
- Participants indicated how very important their friends and families were to their recovery. The loss of friendships following their head injury and difficulty meeting new people was/is one of the most challenging adjustments for them to make;
- Participants indicated that the system for obtaining information about TBI services in the District and then accessing these services was difficult even for persons without a TBI, and even more confusing for a person whose thinking is “tangled;”
- Other identified issues included the length of time it takes to get an appointment; differing eligibility criteria for various programs; and the difficulty in getting questions answered—several respondents felt that some people [providers] were simply unwilling to help;
- There was a consensus that the system is impenetrable and needs to be changed to better meet the needs of TBI survivors and their loved ones;
- There was a general consensus that employment was necessary for TBI survivors to regain their independence and that a broader array of employment opportunities was needed, including volunteer opportunities, in order to accomplish this. Even when employment was available, most agreed that the types of jobs available were not often appropriate to their training and education;
- The need for increased awareness of TBI, especially among service providers, was shared by most respondents. They felt that a screening tool and training/education would be helpful for others to recognize and help them receive the appropriate services;
- Recommendations included that Mental Health needs to adopt a broader definition of TBI so it can be accepted as a qualifying diagnosis. They also agreed that an Interstate Consortium for TBI services would be helpful in order to coordinate and streamline the provision of services.

TBI Organization/Agency Survey Findings

- Eleven Organizations/Agencies reported providing services to an estimated total of 650-1200 TBI survivors and/or their families, providing at least one service during the previous twelve months;

- When asked to indicate their level of interest in a training presentation for their organization to teach basic TBI facts, signs and symptoms, most (73%) indicated at least a moderate level of interest in receiving training;
- The largest service gaps identified by organizations/agencies completing the on-line questionnaire were the need for TBI services for the homeless population; housing assistance; services that promote independent living; and employment assistance/job training.

Introduction

Traumatic brain injury (TBI) is a significant public health problem in the United States. It is estimated that about 5.3 million Americans have a TBI-related disability. TBI can happen to anyone; however, young children, males, active-duty soldiers, and older individuals are especially at risk. The long-term consequences of TBI include altered cognition, personality, and behavior as well as sensory and motor impairments. It is often referred to as a “hidden” or “silent epidemic” because damage to the brain from a TBI is hidden from view and the complications that affect thinking, sensation, language, or emotions may not be readily apparent. Additionally, awareness about TBI among the general public is limited and many health care professionals, service providers, and community service workers are unaware of TBI’s impact¹.

TBI Definition: Traumatic Brain Injury (TBI) is defined by the Centers for Disease Control and Prevention (CDC) as an injury resulting from a blow or jolt to the head, or a penetrating injury to the head, that disrupts the function of the brain. Not all blows or jolts to the head result in a TBI. The severity of such an injury 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.² A TBI can result in short or long-term problems with independent function.

TBI Causes: Nationally, falls (35.2%), motor vehicle-traffic (17.3%); struck by/against events, which include colliding with a moving or stationary object (16.5%); and assaults (10%) were the primary TBI-related causes of emergency department visits, hospitalizations, and deaths by external cause from 2002-2006. Falls resulted in the highest number of TBI-related emergency department visits, and motor vehicle-traffic crashes are the leading cause of TBI-related death.

National TBI Estimates³

In the US for the period 2002 to 2006, an estimated 1.7 million people sustained a TBI annually. Of them:

- 52,000 die
- 275,000 are hospitalized
- 1.365 million, nearly 80%, are treated and released from an emergency department.

TBI is a contributing factor to nearly one-third (30.5%) of all injury-related deaths.

The estimated 1.7 million TBI-related emergency department visits, hospitalizations, and deaths that occur each year in the United States represents a 21 percent increase from 1.4 million TBI-related emergency department visits, hospitalizations, and deaths reported in the previous edition

¹ Traumatic Brain Injury. Institute of Medicine. Available at: <http://www.iom.edu/Activities/Workforce/traumaticbraininjury.aspx>; downloaded 6/9/2010

² Center for Disease Control and Prevention: Traumatic Brain Injury <http://www.cdc.gov/traumaticbraininjury/>

³ Faul M, Xu L, Wald MM, Coronado VG. *Traumatic Brain Injury in the United States: Emergency Department Visits, Hospitalizations and Deaths 2002–2006*. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2010

of *Traumatic Brain Injury in the United States: Emergency Department Visits, Hospitalizations and Deaths*, published by CDC for the period 1995 to 2001.

District TBI Estimates

The District of Columbia currently has one of the highest incidence rates of TBI in the United States. According to the CDC Report, *Preliminary Estimated Annual Rates and Numbers of TBI by State (2000)*, DC has the sixth leading fatality rate due to TBI. Additionally, the District has the fifth highest rates of TBI disability in the US. In 2008, Mayor Adrian Fenty designated the DC Department of Health's (DOH) Community Health Administration as the lead agency to identify survivors of TBI and their families; implement a community-wide needs and resources assessment; and develop a TBI State Action Plan that addresses the coordination of services for this diverse population.

District of Columbia Data⁴

The District of Columbia does not have a Trauma Registry or a standardized method of data collection to effectively monitor the number and type of TBI incidents that occur each year. However, according to a survey about the health of adults residing in Washington DC conducted in 2004, about 22% of respondents reported having had a concussion or head injury at some time in their life. This translates to approximately 98,000 District adults ages 18 and older in 2004 reporting ever having had a head injury or concussion. Other findings from the survey included:

- Men had almost twice as many head injuries or concussions compared to women.
- Younger adults had almost three times as many head injuries or concussions as older adults.
- Slightly more White persons reported a head injury or concussion compared to Black persons.

Only small differences were seen in the prevalence of head injury or concussion by education and income status.

TBI Cross-Cutting Issues/Concerns

Traumatic Brain Injury is also a public health problem with intersecting psychosocial and behavioral concerns, issues, and consequences including:

Homelessness – TBI is particularly common within the homeless population. Homeless persons are at risk of brain injury due to exposure to violence, the high incidence of trauma and accidents, and the prevalence of substance abuse within this population. Neuro-psychiatric and behavioral deterioration following TBI may lead to homelessness.⁵

⁴ District of Columbia 2004 Annual Report, Behavioral Risk Factor Surveillance System (BRFSS).

⁵ American Public Health Association; Politics Policy and Public Health:
http://apha.confex.com/apha/135am/techprogram/paper_151460.htm

Domestic violence⁶ - The head and face are among the most common targets of intimate partner assaults, and victims of domestic violence often suffer head, neck and facial injuries. Batterers seldom assault their partners only once. Common forms of physical assault that can cause a brain injury include:

- Forcefully hitting partner on the head with an object.
- Smashing his/her head against a wall.
- Pushing his/her the downstairs.
- Shooting or stabbing his/her in the head.
- Shaking his/her – which moves his/her brain in a whip-lash motion, smashing it against his/her skull
- Obstructing the airway, causing loss of oxygen to the brain, such as strangling/choking

Economic costs and unemployment - Direct medical costs and indirect costs such as lost productivity due to TBI total an estimated \$60 billion in the United States annually. TBI has a significant effect on future employment.⁷

Co-morbidities and Other factors: Rates of diabetes, high blood pressure, heart disease, asthma, stroke, tobacco use and substance abuse are often higher among TBI survivors.

TBI and Military Personnel/Veterans – According to the CDC website on traumatic brain injury, blasts are a leading cause of TBI among active duty military personnel in war zones. Other literature has labeled TBI a signature injury of the wars in Iraq and Afghanistan. According to the Joint Theater Trauma Registry, compiled by the U.S. Army Institute of Surgical Research, 22 percent of the wounded soldiers from these conflicts who have passed through one military Medical Center had injuries to the head, face, or neck. This percentage can serve as a rough estimate of a portion of returning military having a TBI, although the true proportion is probably higher, since some cases of closed brain injury are not diagnosed promptly⁸

Since military operations began in 2001, more than 1.5 million U.S. military personnel have deployed to Iraq or Afghanistan, and head/neck injuries have been reported in one-quarter who were evacuated. Concern has emerged about the possible long-term impacts of mild traumatic brain injury, or concussion, characterized by brief loss of consciousness or altered mental status, from deployment-related head injuries, particularly those resulting from proximity to blast

⁶ New York State Office for the Prevention of Domestic Violence:
<http://www.opdv.state.ny.us/professionals/tbi/intersection.html>

⁶ Journal of the International Neuropsychological Society: Workers' risk of unemployment after traumatic brain injury: a normed comparison: <http://www.ncbi.nlm.nih.gov/pubmed/16248910>

⁶ BrainLine.Org: Preventing, Treating and Living with a TBI: Substance Abuse and Traumatic Brain Injury: <http://www.brainline.org/content/2009/03/substance-abuse-and-traumatic-brain-injury.html>

⁷ Journal of the International Neuropsychological Society: Workers' risk of unemployment after traumatic brain injury: a normed comparison: <http://www.ncbi.nlm.nih.gov/pubmed/16248910>

⁸ Okie S. Traumatic Brain Injury in the War Zone. NEJM 352:2043-2047. Available at <http://content.nejm.org/content/full/352/20/2043?>

explosions. For example, one study of returning military personnel found that of 2,525 respondents, 124 (4.9%) reported injuries with loss of consciousness and 260 (10.3%) reported injuries with altered mental status⁹. Another study found that about 12% of 2,235 respondents reported mild TBI history, common among veteran injured by bullets/shrapnel, blasts, motor vehicle crashes, air/water transport, and falls¹⁰. These figures translate to 10-12 percent of 1.5 million U.S. military personnel, an estimated 150,000-180,000, returning with at least a mild TBI.

TBI Services Available in the District of Columbia

Currently, there are limited services available to District residents with traumatic brain injury and their families. These services consist of the Brain Injury Association of Washington, DC (BIADC) which has recently become a 501(3) (C). They provide assistance to residents with TBI and their families either by mail, telephone and email info@biadc.org.

The University Legal Services for DC Protection and Advocacy are a collaborative partner with the TBI Program. University Legal Services (ULS) is the federally mandated Protection and Advocacy Agency (PA) for the District of Columbia. ULS provides outreach and legal advocacy for individuals with traumatic brain injuries in the District of Columbia, as well as education to the general public about the various resources, services and supports that are available for consumers with TBI. ULS also has available a ULS and PA Resource Guide. The guide provides information on the services and supports available to residents with TBI and their families.

The TBI Program has a revised Traumatic Brain Injury Resource Guide (2nd Edition) for the District of Columbia. The guide is not only comprised of the supports and services in the District of Columbia, but also those in the surrounding Metropolitan Area, including Maryland and Virginia. The latest edition includes a listing of Homeless Shelters and Transitional Housing for the homeless population of the District which includes persons with TBI. The program is currently working toward establishing a DOH website for the Resource Directory. The website is in its design and approval process. It is anticipated that the website will be available to the public by early fall.

District of Columbia TBI Implementation Grant

The Federal TBI program was created by the Traumatic Brain Injury Act of 1996 (P.L. 104-166) and was later re-authorized as Title XIII of the Children's Health Act of 2000 (P.L. 106-310). The legislation provides for state-based grant programs charged with improving service delivery, establishing policy, and securing the financial support to bring about lasting systems change in the care of persons with TBI¹¹. HRSA is the designated granting agency for the state programs.

⁹ Hoge, C. W., McGurk, D., Thomas, J. L. Cox., A. L. Engel, C. C. Castro, C. A. (2008). Mild Traumatic Brain Injury in U.S. Soldiers Returning from Iraq. *NEJM* 358:453-463.

¹⁰ Schneiderman AI, Braver ER, Kang, HK. Understanding sequelae of injury mechanisms and mild traumatic brain injury incurred during the conflicts in Iraq and Afghanistan: persistent postconcussive symptoms and posttraumatic stress disorder. *Am J epidemiol.* 2008 Jun 15;167(12):1446-52.Epub 2008 Apr 17:

¹¹ <http://www.iom.edu/Activities/Workforce/traumaticbraininjury.aspx>.

Purpose

The goal of the District of Columbia Traumatic Brain Injury (TBI) Implementation Project is to assess and mitigate the challenges faced by adults living with TBI, including the homeless population. Homeless individuals, including women receiving services from domestic violence shelters, are at ongoing risk for head injury. Additionally, a number of these homeless are believed to be veterans who may have sustained head injuries and/or post traumatic stress disorder (PTSD) from their military service. Anecdotal evidence suggests that the rate of head injury (recent and remote) may be quite high among veterans and that TBI rarely is diagnosed or rehabilitated, leaving these persons with substantial unmet needs. However, no reliable or local data exists to guide decisions as to what services are needed or the total number of people affected. The District of Columbia does not have a comprehensive system of care to address the needs of children, adolescents, and adults with TBI.

The DC TBI Implementation study was undertaken to gather evidence from four distinct groups: 1) Individual Surveys conducted of homeless persons, with and without traumatic head injury, including military veterans and women receiving services from domestic violence shelters, to determine unmet needs for programs and services; 2) Provider Surveys of workers at the shelters where the individual surveys were done to identify specific types of services provided there; 3) Focus Groups to gather information about informal supports, challenges/gaps in services experienced by TBI survivors/family members and recommendations for improvement; and 4) TBI Organization/Agency Surveys to assess individuals' perceptions who work at TBI-serving agencies and organizations about the needs and priorities for TBI survivors and their families, how well needs are being met, and what could be done in the District to address unmet needs.

Methodology Individual Surveys. A comprehensive assessment was conducted of homeless adults residing in the District of Columbia ages 18 and older who were either receiving services from a homeless shelter, or a women's shelter, or who were without shelter at the time of the interview during summer 2009-winter 2010. The principal template for our survey was the *Traumatic Brain Injury among Homeless Adults in the District of Columbia Homeless Needs and Resource(For Individuals)* a self-report survey, which included approximately 120 variables including demographic information; history and type of head injury; severity indicators; military veteran status; current problems related to prior head injury; medical care received; information, services, and supports received; length of time homeless, and employment/training needs.

The Traumatic Brain Injury among Homeless Adults in the District of Columbia Homeless Needs and Resource survey instrument modified the federal TBI survey template to measure District of Columbia-specific information. Based on the results of a pilot study conducted in June 2009, the survey instrument was further modified by changing the order of several of the questionnaire items and adding questions to capture alcohol and/or drug use information.

Limitations of the Data

A convenience sample was utilized in conducting this study. The homeless shelter first had to agree to provide space for the interview process and take time away from their program activities

to permit respondents to participate. Not all shelters had extra space or flexibility to rearrange their schedules. Also, many homeless shelters in the District of Columbia are open only at night when clients sleep and are closed during the day, making it difficult to make arrangements for interviews. Regarding the survey instrument, the measures of brain injury rely on unconfirmed self reports and are subject to recall bias.

Population and Study Design

The Traumatic Brain Injury among Homeless Adults in the District of Columbia Homeless Needs and Resource assessment utilized a cross-sectional survey design that incentivized respondents in the form of a \$10 prepaid gift card if they passed the screening for brain injury and completed the entire questionnaire. Due to concerns that respondents were over-reporting head injuries to qualify for the gift card, this process was later modified to provide gift cards to all respondents, regardless of whether or not they reported a head injury.

Project staff made an effort to contact a total of 32 homeless shelters by telephone from a comprehensive listing of shelters contained in the Resource Directory. In most instances, facilities were called multiple times before TBI project staff were able to speak with someone having the authority to schedule dates and times to interview homeless residents. Other barriers included shelters that did not return calls; some shelter providers who had fears about client confidentiality; and other shelter providers who felt the survey was inappropriate for their residents because they believed residents did not have a TBI.

Once a time for interviews was scheduled, a group of TBI project staff traveled to the homeless facility to conduct face-to-face interviews. Initially, the interview was a three-step process. First, participants were asked to read and sign an Information and Consent form. After signing, respondents were screened by another interviewer to determine the presence of head injuries and also to collect information on demographic and health characteristics. If the respondent self-reported a head injury, they then went to a third interviewer to elicit specific information about brain injury severity as well as needed services and supports. However, due to staffing and time constraints, beginning July 2009, the three-step process was modified to one-step so that each interviewer administered all three components of the interview.

Trained interviewers from the District of Columbia Department of Health and student interns from George Washington University administered face-to-face surveys beginning June 21, 2009 and ending February 27, 2010. However, the final round of interviews conducted in February utilized an unstructured process—interviews were conducted outdoors at a local park, instead of at homeless shelters, and a number of the surveys were distributed for respondents to fill out on their own following verification that Information and Consent forms were signed.

A positive screen for traumatic brain injury was defined using the following criteria:

- Respondent identified at least one head injury and the presence of one or more indicators of current health conditions related to the past head injury; or
- Respondent indicated they were ever seen by a doctor, in the emergency room, or in the hospital because of an injury or trauma to the head; or

- Respondent was diagnosed by a health provider with a head injury/traumatic brain injury; or had ever been diagnosed with a concussion.

From the initial data file of 209 completed survey interviews (which includes the pilot group), 10 were removed due to duplicate surveys (7) and incomplete information (3). The final survey population consisted of 199 individual homeless adults in the District of Columbi

Findings Individual Surveys

*Age not recorded for 1 person; **Race/ethnicity not recorded for 1 person; ***Education not recorded for 1 person

TBI Status (all respondents)	N = 199	%
Positive History of TBI	129	64.8
No History of TBI	70	35.2
Table 1. Demographic Characteristics of TBI Participants, District of Columbia 2009-2010		
Characteristic	N = 129	(%)
Age*		
< 45 years old	43	33.3
≥ 45 years old	85	65.9
Minimum	19	-
Median	48	-
Maximum	71	-
Gender		
Male	101	78.3
Female	27	20.9
Other	1	< 1.0
Race/Ethnicity**		
Black, Non-Hispanic	110	85.3
White, Non-Hispanic	3	2.3
Hispanic (any type)	9	7.0
Other	6	4.7
Level of Education***		
Less than High School	41	31.8
High School Diploma/GED	51	39.5
Post Secondary	36	27.9
Marital Status		
Single, never married	94	72.9
Married	7	5.4
Separated/Divorced	26	20.1
Widowed	2	1.6
Family Status		
Has Children	79	61.2
Current length of time homeless		
Mean	3.4 years	-
Median, Mode	1 year	-
Veteran Status (males, only)	N = 101	
Veteran	22	21.7
Non-veteran	64	63.4
Data Missing	15	14.9

Lifetime prevalence for homeless participants for any head trauma was 64.8%. The demographic characteristics of homeless individuals reporting a history of head injury are described in Table 1. Respondents reporting a history of head injury were predominantly older (at least half were 48 years of age or older); African American, non-Hispanic (85.3%); males (78.3%); and high school graduates/GED certificate holders or above (67.4%). One person indicated having a Trade License; four individuals reported having a Bachelor’s degree; and one person reported having a Master’s degree. About 7 percent reported Hispanic ethnicity. The majority (72.9%) of respondents reporting a history of head injury were single, never married and over half (61.2%) were parents. Number of children ranged from 1 to 12, with about half (48.1%) reporting 1-3 children. None of the respondents indicated their child resided with them. . Current length of time homeless in Washington DC ranged from 1 week to 39 years, averaging 3.4 years with a median and mode of 1 year.

Nearly one-fourth (21.8%) of male respondents reporting a head injury were veterans, having served in the US military or the Reserves. Among those respondents reporting military service-related TBI, three had served in Viet Nam; one individual had served in the USA and Germany; and one individual had served in the Army Reserves.

Table 2. Self-Reported Causes of TBI (n=199)		
Cause	N	(%)
Fight/Assault	72	36.2
Fall	55	27.6
Motor Vehicle Crash	37	18.6
Domestic Violence	29	14.6
Bicycle Accident	27	13.6
Physical Abuse	23	11.6
Suicide Attempt	21	10.6
Near Drowning	21	10.6
Sports Accident	17	8.5
Child Abuse	15	7.5
Strangulation	15	7.5
Medical Condition	13	6.5
Gunshot/Firearms	10	5.0
Hit, struck by an object	8	4.0
Cut/pierce	1	<1.0

When asked if the above (Table 2) causes of head injury ever happened to them, respondents most frequently reported fights or assaults (36.2%); falls (27.6%); and motor vehicle crashes (18.6%). These causes of head injury reported by homeless adults have remained consistent over the course of the implementation study for the District.

TBI Severity. Among respondents reporting a history of head injury, the TBI severity indicators measured on the needs assessment included feeling dazed, confused, dizzy, or unable to remember being injured right after the head injury (68%); currently being treated by a doctor or therapist for any head injury (23%); and/or loss of consciousness (64%).

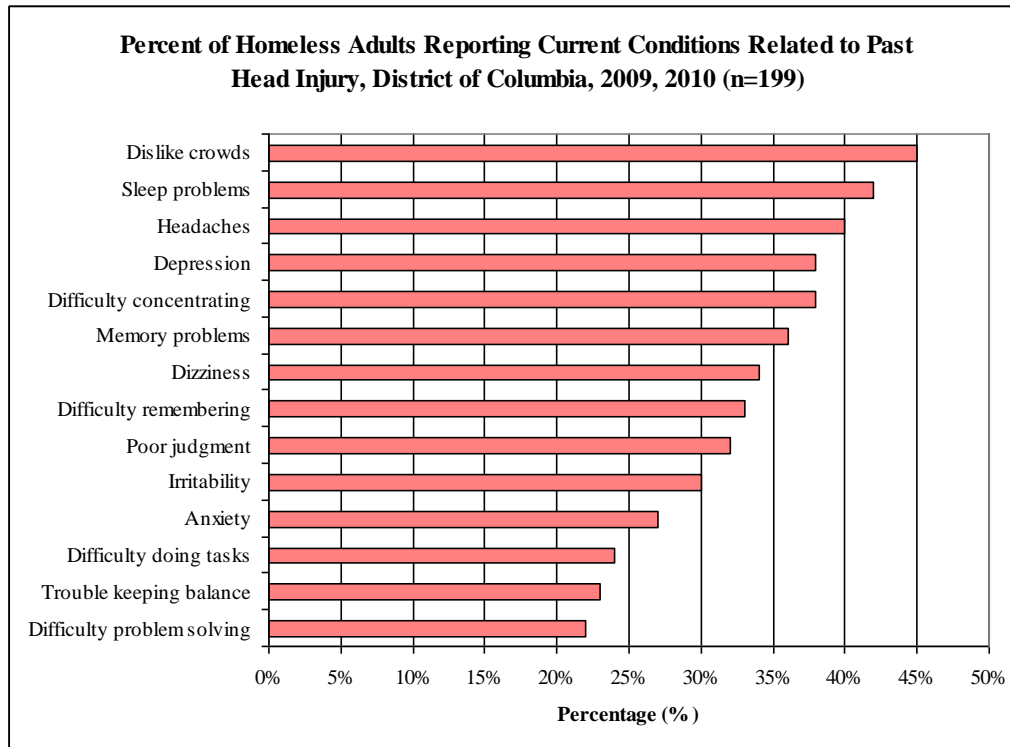
TBI and Chronic Conditions. In Table 3 below, results indicated that TBI respondents reporting a history of head injury were significantly more likely to be current cigarette smokers compared to respondents without a history of TBI ($X^2 = 15.398$; $p < .001$). Table 5 shows a statistical association between TBI respondents to have ever been diagnosed with high blood pressure ($X^2 = 8.756$; $p = .003$) compared to non-TBI respondents. Table 7 indicates TBI respondents to be significantly more likely to have ever have been diagnosed with asthma ($X^2 = 6.906$; $p = .009$). These findings suggest that TBI survivors who are homeless may be more likely to have nicotine addiction, high blood pressure, and/or asthma. Over half (114, 57%) of current smokers indicated they wanted to stop smoking and/or that they wanted help to quit smoking. Specific service needs to address these conditions include tobacco cessation products and programs; medication and treatment options for high blood pressure; and asthma management best practices for homeless healthcare providers.

Table 3. TBI Status by Smoking Status (N=199)		
Current Smoker	(+) TBI Screen	(-) TBI Screen
Yes	106 (82.8%)	40 (57.1%)
No	22 (17.2%)	30 (42.9%)
$\chi^2=15.398$ (p<.001)		
Table 4. TBI Status by Diabetes Status (N=196)		
Diabetic	(+) TBI Screen	(-) TBI Screen
Yes	22 (17.3%)	6 (8.7%)
No	105 (82.7%)	63 (91.3%)
$\chi^2=2.718$ (p=.099)		
Table 5. TBI Status by Hypertension Status (N=197)		
Hypertensive	(+) TBI Screen	(-) TBI Screen
Yes	57 (44.5%)	16 (23.2%)
No	71 (55.5%)	53 (76.8%)
$\chi^2=8.756$ (p=.003)		
Table 6. TBI Status by Heart Disease Status (N=196)		
Heart Disease	(+) TBI Screen	(-) TBI Screen
Yes	15 (11.8%)	3 (4.3%)
No	1112 (88.2%)	66 (95.7%)
$\chi^2=2.367$ (p=.124)		
Table 7. TBI Status by Asthma Status (N=196)		
Asthmatic	(+) TBI Screen	(-) TBI Screen
Yes	33 (26.0%)	7 (10.1%)
No	94 (74.0%)	62 (89.9%)
$\chi^2=6.906$ (p=.009)		
Table 8. TBI Status by History of Stroke (N=195)		
History of Strokes	(+) TBI Screen	(-) TBI Screen
Yes	15 (11.9%)	6 (8.7%)
No	111 (88.1%)	63 (91.3%)
$\chi^2=0.478$ (p=.489)		

From a checklist (Figure 1), all respondents were asked to identify whether they had any current behavioral ailments that they thought might be related to their past head injury. Figure 1 below shows the percentage of respondents reporting these behavioral and health conditions. The most

frequently reported conditions included a dislike of being in crowds (45%); sleep problems (42%); and headaches (38%).

Figure 1. TBI and Current Conditions



TBI Information Received. Respondents reporting a history of head injury were asked to indicate from a checklist (Figure 2), resources that had provided them with information on head injury. The three most frequently cited information sources were health care providers (36%); pamphlets/ brochures (26%); and case manager/counselors (26%). Most of the respondents with a history of brain injury (83%) indicated they would like to know more about brain injury effects and were interested in using the computer to learn more about services and other support information (71%).

Consistent with pilot group findings, less than half the respondents with a history of brain injury indicated they had ever received information from any of the listed sources (health care provider, pamphlets, case managers, fact sheets, employer, internet, or library), indicating a lack of critical information regarding traumatic brain injury. Nearly three-quarters (71%) knew where to go if help were needed for their head injury, and when asked to indicate where they would go, reported doctors, clinics, hospitals, the ER, etc. This suggests that although The DC Healthcare Alliance, a public program offering a full range of health care services for uninsured residents is impacting this population regarding acute incidents, efforts to provide information on other available services including primary care, vision care, and adult wellness programs would be helpful as well.

Figure 2. TBI and Information Resources

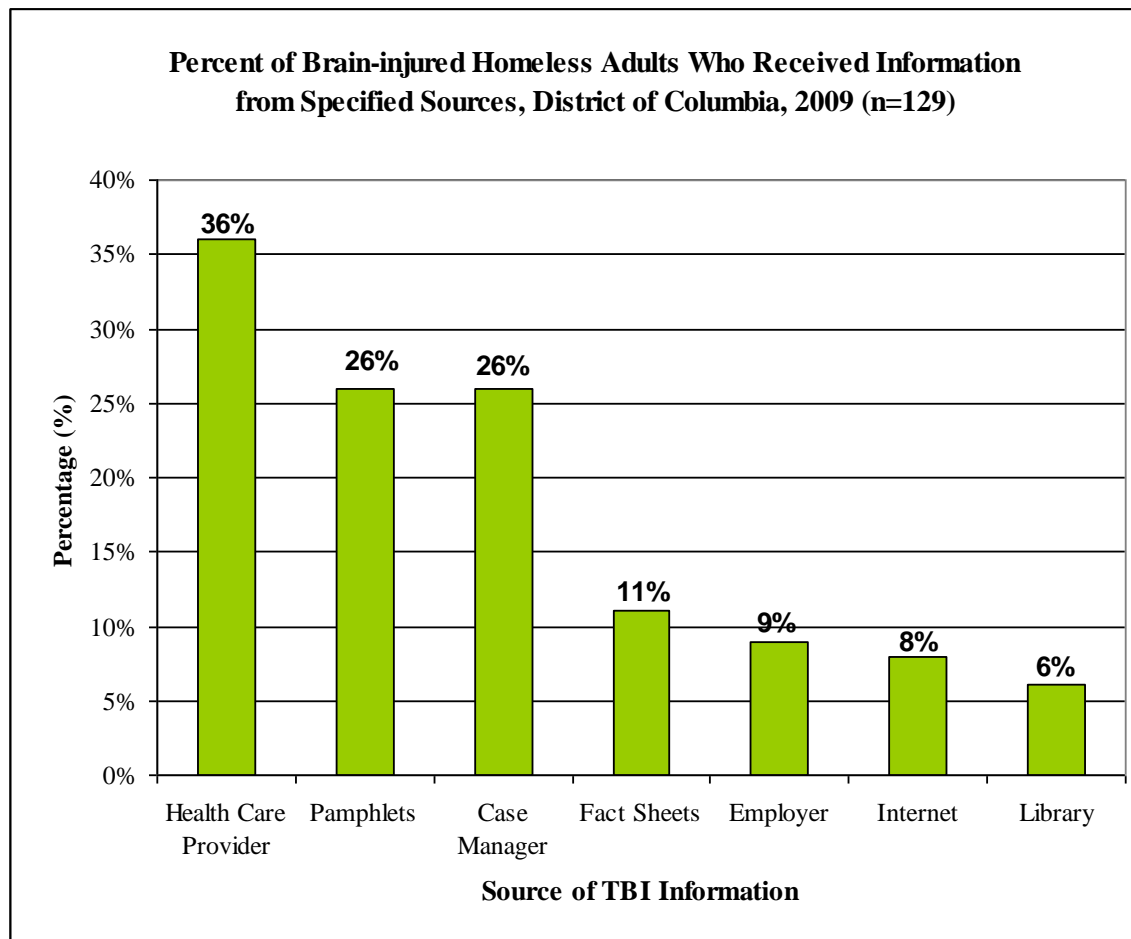
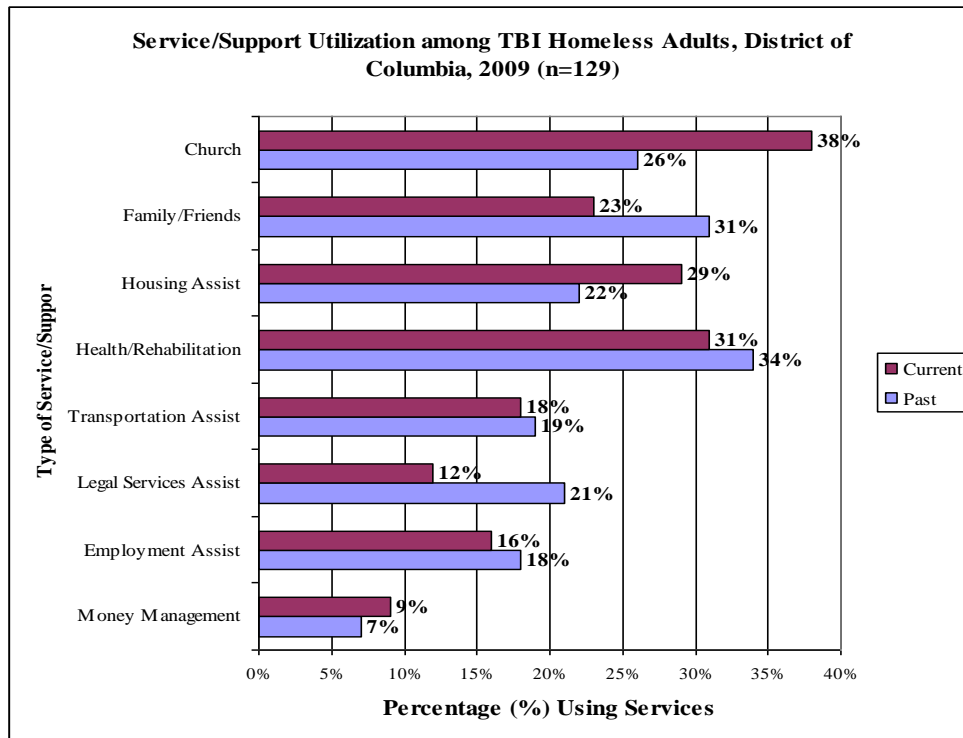


Figure 3. TBI Services and Supports



As shown above (Figure 3), only about one-fourth to one-third of homeless respondents with a history of head injury reported receiving needed supports. The most frequently reported services and supports utilized by brain injured homeless adults included help from the church (38%); health and rehabilitation services (31%); and housing assistance (29%). Other types of services and assistance reported by respondents included soup kitchens, shelters, public assistance, and disability.

TBI and Employment. 85% of the homeless adults with a history of brain injury are unemployed. Almost half (47%) reported they currently are looking for employment.

The most frequently reported barriers experienced by those brain injured homeless adults who currently are looking for employment are transportation needs (n=55) and job training needs (n=44). Other barriers reported by these respondents included the following:

Personal concerns

- Has eczema
- Hard to concentrate
- Lack of education (3)
- Neck pain
- Needs appropriate clothing
- Memory loss from injury
- Age
- Needs stability, seeking housing

Communication

- Needs a phone
- Difficult to contact/find out about jobs
- Inability to use a computer (2)

Economy

- The economy affects hiring practices (5)
- Inability to find appropriate work (security, restaurant, driver)

Legal issues

- Criminal history
- Citizenship

Conclusions

This study found a high lifetime prevalence (64.8%) of brain injury among a convenience sample of homeless adults in Washington DC. This rate is nearly 8 times higher compared to the 8.5 percent lifetime prevalence found in a New Haven probability sample.¹²

The most frequently reported health and behavioral issues (reported by one-third or more of respondents) included dislike of being in crowds; sleep problems; headaches; depression and difficulty concentrating. These were issues that most likely could be addressed by a variety of services and supports that already are available and covered by the DC Healthcare Alliance. Although nearly three-fourths indicated they knew where to get help, primarily from hospitals, having more information about the full range of services and supports available could encourage them to seek these services.

Methodology Homeless Service Providers Survey

The *Traumatic Brain Injury among Homeless Adults in the District of Columbia Homeless Needs and Resource (For Providers)* assessment of homeless shelter providers was conducted at shelters where the individual surveys were done. This survey instrument contained approximately 10 items asking the provider to provide information on types of services provided; whether services were provided on-site; services/supports they believed were needed by TBI survivors; referrals to other agencies; and TBI awareness training needs. As with the individual surveys, the homeless service providers were asked to read and sign an Information and Participant Consent form and received a \$10 gift card for completing the survey. A total of 12 interviews were conducted at the following shelters from May 2009 through January 2010:

¹² Silver JM, Kramer R, Greenwald S, Weissman M. The association between head injuries and psychiatric disorders: findings from the New Haven NIMH Epidemiologic Catchment Area Study. *Brain Inj* 2001;15:935-45. abstract available at <http://www.ncbi.nlm.nih.gov/pubmed/11689092?dopt=Abstract>

Homeless Service Providers Survey Findings

Table 9. Homeless Shelter Facilities by Number of Staff Interviewed, Average Number of Clients Served Each Day or Night, and Average Estimated Number of Clients having TBI, District of Columbia, 2009-2010.

Facility Type	Number of Interviews	Avg # Clients	Avg % TBI
Men's Day Program	2	75-130	0-8%
Women's Day Center	1	40	5%
Women's Overnight Shelter	1	100	DK
Work Bed Program	2	75	0-3%
Overnight Shelter	2	90	0-24%
Transitional Housing	2	40	25-50%
Men's Hypothermia Shelter	1	47	17%
Women's Emergency Shelter	1	118	80%
Total	12	75	19%

Homeless providers reported sheltering a range of 40-130 individuals on any given day or night, an average of 75 individuals. Of these, providers estimated approximately 0-80% of these individuals could be TBI survivors. When asked if they or staff members had received any training and education on TBI or head injury, only one provider (8%) indicated they had received training, and all (100%) indicated their belief that staff would benefit from TBI training.

When asked to respond to a series of different types of services and assistance provided to their clients, providers reported their organization most frequently provides the following types of services/assistance:

- Housing assistance (n=9)
- Employment assistance (n=9)
- Transportation assistance (n=9)
- Money management services (n=8)

When asked to respond to the same series of items for different services and assistance they believed were most needed by homeless individuals with TBI, providers most frequently indicated the following:

- Individual counseling (n=9)
- Mental health counseling (n=9)
- Housing assistance (n=9)
- Medical care (n=9)
- GED/High school diploma (n=9)
- Vocational training (n=9)
- Nutrition (n=9)

92% of the shelter providers (11) reported that their agency refers clients to a number of health/mental health services outside the organization. The following outside referrals were most frequently reported being provided to homeless clients for health/mental services:

- Anchor Mental Health Association (4)
- Department of Mental Health (3)
- Andromeda (2)

83% of shelter respondents (10) also indicated their agency provides support programs for underserved racial, ethnic, and age groups. The following types of support groups/services were reported:

- Substance abuse groups (9)
- Social/Life skills (5)
- Housing programs/support (5)
- Education (3)
- Employment (4)
- Immigration services/Legal (2)
- HIV testing/support (2)
- Case management (1)

Focus Group Methodology

The DC Brain Injury Association, Inc. (DCBIA) support group hosts their monthly meetings at the DC National Rehabilitation Hospital (NRH), located in Washington DC. The support group provides a forum for brain injury survivors, NRH staff members, caregivers, and family members of survivors including spouses and parents to connect with each other to talk about their experiences and to obtain information on some of the local resources that are available. The structure of the support group is fluid—attendees are encouraged to drop in and stay for as long as they wish, if even for a few minutes.

TBI Project staff members and TBI Advisory Committee members were invited to attend the NRH TBI monthly support group meeting on Wednesday May 19, 2010. The purpose of the focus group session was to determine the availability of resources provided to persons with TBI and their families, as well as the gaps in services that exist in the current system of support.

One of the TBI Advisory Committee members, Paul Rubenstein, who is a TBI survivor himself, facilitated the focus group session. Questions were developed by Dr. Norman Gold, Clinical Psychologist, TBI caregiver, and a member of the TBI Advisory Committee with input from other TBI Advisory members and the DOH TBI team. The proposed questions were reviewed for appropriateness and social/cultural sensitivity, not only by the Advisory Committee, but also by Dr. Anjali Talwalkar, the CHA Deputy Director for Programs and Policy; and Amy Horn Groenendaal, Research Analyst for the National Opinion Research Center (NORC). The final list of questions contained six subject headings: introductions; informal supports; challenges confronted with when looking for support and services; gaps in services experienced by TBI survivors/family members; suggested improvements in services and supports; and other recommendations.

At the beginning of the session, focus group respondents read and signed Participant Consent forms agreeing to participate (n = 18). Those who turned in a signed consent form received a \$10 gift card for their participation (n = 18) at the end of the session. Demographic sheets also were distributed, however, only nine (9) completed sheets were returned for analysis. Several of the younger participants who arrived toward the end of the session did not fill out demographic sheets and others who left early did not return their sheets. Thus, a number of respondents whose opinions are presented in the focus group findings are not reflected in the participant demographic section.

Data from the District of Columbia NRH TBI demographic sheets were analyzed using Statistical Package for the Social Sciences (SPSS) version 16.0 and data from the focus group session was analyzed by the project's TBI epidemiologist by coding responses from notes recorded during the focus group session. Results were checked for consistency by a second analyst.

Focus Group Findings

Focus Group Participant Demographics

About two-thirds of the NRH focus group participants who completed the demographic sheets reported they were TBI survivors (67%).

Most (67%) focus group members were female; the average age was 45.3 years, (though as previously noted, the younger participants arrived near the end of the session and did not complete demographic sheets); and the majority (89%) of respondents were white.

This group reported high levels of education—most (78%) were college graduates with degrees—BA (2); Master’s (3); and PhD (1).

The majority (56%) of respondents were single, never married.

The most frequently reported type of health care coverage for the TBI survivor was public insurance such as the DC Healthcare Alliance, Medicaid, and Medicare (67%).

Table 10. Demographic Characteristics of TBI Focus Group Participants, District of Columbia, 2010 (n = 9)

<u>Characteristic</u>	<u>Number</u>	<u>Percent</u>
TBI status		
TBI survivor	6	67%
Family caregiver	2	22%
Works w/TBI client	1	11%
Gender		
Male	3	33%
Female	6	67%
Age Group		
20-29	2	22%
30-39	2	22%
40-49	2	22%
50+	3	34%
Race		
African American	1	11%
White	8	89%
Education		
HS graduate/GED	1	11%
Some college	1	11%
College graduate	7	78%
Marital Status		
Single, never married	5	56%
Married	3	33%
Widowed	1	11%
Insurance Status of person with TBI		
Private insurance	3	33%
Public program (Allied, Medicaid, Medicare)	6	67%

Results of the focus group analysis identified four (4) main TBI themes: the importance of social networks/informal systems of support; system navigation issues; employment-related concerns; and lack of training/awareness among providers.

Social Networks/Informal Systems of Support

Participants indicated how very important their friends and families were to their recovery. The loss of friendships following their head injury and the difficulty experienced being able to meet new people was/is one of the most challenging adjustments for them to make.

Family Support

- My wife acted as my personal rehabilitation coordinator—it was hard on her (and my son), but the best thing that could have happened for me
- I'm appreciative of my wife and children
- My parents

Friends/Volunteers Support

- I had a network of friends who would drop in and ask if I wanted to go grocery shopping, for hair cuts, etc—it was almost like having respite, but informal
- There was always a cluster of people willing to drive if my child needed to go to outpatient rehab
- Volunteers to drive me to physical and occupational therapy
- After my injury I was shy—I didn't want to blurt something [stupid] out; I went back to school in a wheelchair and friends driving me to different activities really allowed me to interact with others and helped me get over my shyness
- I had a few friends who really stuck with me; but friends who had not experienced hardship in their own lives didn't know what to say or how to act around me. But that was their issue, not mine and once I got my life back I didn't hold it against them

Other Support

- Loving, caring professors at the community college where I received paraprofessional training made all the difference for me

Social/Networking Challenges

- In the community, it is difficult to be able to be in touch with others like ourselves
- Finding kindred spirits and social networks
- Peer support—someone who is understanding of where you are in your life
- It is hard for friends to understand the fatigue, the limitations and that I don't have the stamina to talk on the phone for very long

- Sometimes you have to make a new circle of friends—you're a different person now; accept it and go actively to establish new relationships
- I am in touch with almost none of my friends. No one “got” me and I didn't even understand myself. Life has been challenging and one big challenge for me is keeping in touch with friends

System Navigation Issues

Participants indicated that the system for obtaining information about TBI services in the District and then accessing these services was difficult even for persons without a TBI, and even more confusing for a person whose thinking is “tangled.” Other identified issues included the length of time it takes to get an appointment; differing eligibility criteria for various programs; and the difficulty in getting questions answered—several respondents felt that some people [providers] were simply unwilling to help. There was a consensus that the system is impenetrable and needs to be changed to better serve the needs of TBI survivors and their loved ones.

System Issues

- There are too many variables for the end-user of the service to figure out—you meet a hurdle, detour, but it is too much to handle—you need a navigator
- The [system for TBI services] is difficult even without a brain injury. I [the father of a TBI survivor] have a PhD and have been doing this [helping his son get various services] for 16 years and it is still difficult
- I get tangled in my thinking—I'm single, my dad is terminally ill and I'm trying to maintain everything. I have a house and I've heard there are vouchers, but I can't find anything out. It's just too much and then I forget where I left off
- How to maneuver around the system
- Clearinghouse of Information is needed—it is hard to find services then eligibility questions make it more difficult to proceed. Maybe if there was a flow chart that described if you go to this office, this is what you will need
- An entry point is needed (such as with services for seniors) that will ease the frustration with trying to find services; also staffing shortages add to the feeling that things don't work

Services Issues

- I don't know how to use the healthcare system in DC; the system is impenetrable-- after several frustrating phone calls, we ended up with an appointment for the hard-of-hearing, which we did not need
- Cost: why do we have to pay for services?

- Length of time it takes for an appointment; we must wait from now until September for an appointment
- Inaccessibility of the system and I feel that [some] people are unwilling to help

Information Issues

- People needed information “yesterday”

Employment-related Concerns

There was a general consensus that employment was necessary for TBI survivors to regain their independence and that a broader array of employment opportunities was needed, including volunteer opportunities, in order to accomplish this. Even when employment was available, most agreed that the types of jobs available were not often applicable to their training and education.

- At work, I am the only disabled person; there is no support available and my employer will not allow a 3rd party to help me
- There is even a lack of volunteer opportunities—[the TBI survivor] wants to get out of the house more often and I’ve been asking around for volunteer opportunities, but people mostly look at just her disability decide they don’t need her
- We need to practice how to work
- The types of jobs available—you don’t want to do sales work when you have been educated and trained to be a scientist or a professional
- Supported employment—someone trying to transition into the work world from a program needs a lot of support
- Referrals for volunteer opportunities (for the TBI survivor) are needed
- Need help with employment
- Promotion: career/vocational evaluations are needed or a screening tool to help decide what kinds of jobs to do
- Referrals for volunteer opportunities (for the TBI survivor) are needed

Lack of Awareness/Training among Providers

The need for increased awareness of TBI, especially among service providers, was shared by most respondents. They felt that a screening tool and training/education would be helpful for others to recognize and help them receive the appropriate services.

Lack of Awareness among Providers

- There is a lack of training even within the Dept of Rehabilitation—more than once I have been sitting in front of qualified persons who do not recognize my symptoms, even though I am a survivor of multiple brain injuries since the age of three (she is now 40), so it is easy to fall through the cracks
- TBI is a silent epidemic—there is an issue of visibility, especially if you “look fine”
- Limited understanding of providers—my vocational therapist said I could work in a coffee shop even though I had graduated college. It was the therapist who had limited thinking

Training Needs

- Need training of metro station employees—how to help us deal with non-working elevators for example
- Promotion: career/vocational evaluations are needed or a screening tool to help decide what kinds of jobs to do
- Education for service providers is needed or a screening tool
- A standardized screening tool is needed to identify the less visibly impaired TBI sufferers. Many times such patients go undetected due to the lack of understanding by providers.

Focus Group Recommended Systems of Care

Focus group participants agreed that mental health providers need to adopt a broader definition of TBI so it can be accepted as a qualifying diagnosis. They also agreed that an Interstate Consortium for TBI services would be helpful in order to coordinate and streamline provision of services.

Recommended Systems of Care

- Aging in Place Organizations (“**Aging in place**” refers to living where you have lived for years, typically not in a health care environment, using products, services, and conveniences which allow you to remain home as circumstances change. In other words, you continue to live in the home of your choice safely and independently as you get older) - something similar would be useful for TBI (<http://aginginplace.com/>) .
- The DORS program in Maryland: The Maryland Division of Rehabilitation Services (DORS) offers programs and services that help people with disabilities go to work or stay independent in their homes and communities and is an agency of the Maryland state Department of Education (<http://www.dors.state.md.us/DORS/AboutDORS/default.htm>)

- New Jersey MENTOR Program: uses an outcome-focused approach for all of our functional NeuroRehabilitation services and support to help individuals regain their independence and productive lifestyle. At New Jersey MENTOR, we integrate therapies into daily activities in community settings, such as home, school, day programs and the workplace (<http://www.nj-mentor.com/standard/services.aspx?guid=53c3986c-6de6-437d-8f32-3b7beb710e87>)
- The Brain Injury Association of Maryland does a terrific job and has a good Brain Injury Resource Guide—they would be a good template to draw from (<http://www.biamd.org/>)

TBI Organization/Agency Survey Methodology

The purpose of the *TBI Resource Assessment (For Organizations)* was to survey TBI-serving agencies and providers to identify various needs and priorities for TBI survivors and their families; determine how well needs are being met; and to recommend future plans to address unmet needs. The survey instrument contained approximately 12 questions asking the organization/agency to provide information on organization type; estimated count of unduplicated clients; how its programs services are marketed; level of interest in having a training presentation that taught the basics of recognizing TBI; and recommendations for changes in services for specific populations of TBI providers. An additional series of approximately 30 items asked respondents to rank the provision of specific services, where 1 = the lowest score and 10 = the highest score, to indicate how important the provision of that programs/service is for TBI survivors and their families in the District of Columbia. Using the same set of indicators and rankings, respondents next were asked to rate how effectively individuals and their families that have been impacted by TBI are served by these programs/services.

The questionnaire was designed and distributed using SurveyMonkey®, an online survey tool that enables people of all experience levels to create their own surveys quickly and easily; to download results; and/or use the analyze results tool. Prior to survey implementation, the survey tool was reviewed for input by Dr. Talwalkar and Ms. Horn, and Vance Farrow the Interim Bureau Chief for the Bureau of Cancer and Chronic Disease. Also a pre-test was conducted resulting in minor modification of several survey items. The link to the survey was emailed on June 9, 2010 to the 14 members of the TBI Advisory Board with instructions to forward the link to at least five organizations/agencies providing services to TBI survivors and/or their families. Periodic emails were sent reminding Advisory Board members to return responses no later than June 23, 2010. The following analysis is based on 11 completed surveys (where one hospital was represented by five different individuals).

TBI Organization/Agency Survey Findings

Table 11. Homeless Shelter Facilities by Number of Staff Interviews Conducted, Average Number of Clients Served Each Day or Night, and Average Estimated Number of Clients with TBI, District of Columbia, 2009-2010.

Organization/Agency Type	Number of Surveys	Number of TBI Clients
Private Foundation 501 (c) (3) (Outreach)	1	n/a-no clients seen
Private Foundation 501 (c) (3) (Agency/Organization)	1	< 50
Private Foundation 501 (c) (3) (Agency/Organization)	1	100-199
Private Foundation 501 (c) (3) (Agency/Organization)	1	< 50
Hospital	5	200-499
Government Agency	1	200-499
Private Foundation 501 (c) (3) (Protection and Advocacy Agency)	1	< 50
Total	11	

Organizations/Agencies reported providing services to TBI survivors and their families who received at least one service during the previous 12 months to an estimated total of 650-1200 TBI survivors and/or their families. When asked to indicate their level of interest in a training presentation for their organization to teach basic TBI facts, signs and symptoms, 73% (8) indicated at least a moderate level of interest in receiving training.

Table 12 below presents the results for respondents’ rating of the importance and the effectiveness of a series of items reflecting services/assistance for TBI survivors and their families. Average scores first were calculated for each set of items regarding “how important” and “how effective” each type of service/assistance was. Next, the difference between the scores was calculated to indicate the size of the gap in services. For example, a service that is rated highly important (10) and highly effective (10) would receive a neutral score (0); a service ranked low in importance (1) and high in effectiveness (9) would receive a negative score (-8); while a service ranked highly important and low in effectiveness would receive a positive score—larger positive scores indicate larger service gaps.

Table 12. Types of Service/Assistance for TBI Survivors and their Families by Average Rated Scores for How Important, How Effective, and Size of Service Gaps, District of Columbia, 2010 (n = 11).

Types of Service/Assistance	Avg Rated Importance	Avg Rated Effectiveness	Difference (Imp-Eff)
TBI services for the homeless population	8.36	2.67	5.69
Housing assistance	8.36	3.22	5.14

Services that promote independent living	8.7	4.56	4.14
Employment assistance/job training	8.18	4.5	3.68
Respite services for caregivers	6.91	4.25	2.66
Individual counseling	8.18	5.62	2.56
Money management	7	4.5	2.5
Alcohol and substance abuse services	7.82	5.56	2.26
TBI services for the aging population (>50 yrs of age)	6.55	4.38	2.17
Mental health counseling	7.91	5.78	2.13
University	5.55	3.88	1.67
Vocational training	6.55	5	1.55
Community college	5.55	4	1.55
Adult day care	5.64	4.11	1.53
Tracking/Monitoring/Surveillance	5	3.62	1.38
Nutrition services	5.18	3.88	1.3
Medical care	7.82	6.67	1.15
Pain management	6.9	5.75	1.15
Legal services	6.64	5.5	1.14
Dental services	5.18	4.12	1.06
Speech therapy/language pathology	7.36	6.33	1.03
GED/High school diploma	5.9	4.88	1.02
Occupational therapy	7.45	6.67	0.78
Assistive technology/equipment	6.27	5.56	0.71
Follow-up services	8.18	7.56	0.62
Physical therapy	7.27	6.67	0.6
Distance to travel to receive services	6.73	6.22	0.51
Special education services	5.36	4.88	0.48
Trauma system	5.91	5.56	0.35
Transportation assistance	6.82	6.67	0.15
EMS/ambulance service	5	5.57	-0.57

The largest service gaps identified by organizations/agencies completing the on-line questionnaire were TBI services for the homeless population; housing assistance; services that promote independent living; and employment assistance/job training.

Recommendations to better meet the needs of homeless persons with TBI included:

- basic education about TBI to providers of homeless services and supports;
- housing (affordable)/supervised housing for TBI patient population;
- a shelter that could provide more supervision for TBI pts who are unsafe to be left alone;
- resources on where to get info in the community (libraries, etc); resource lists on where to go for care at lower rates (free clinics, medical shelters) and places with durable medical equipment available (wheelchair society);
- tracking of persons hospitalized for a TBI;
- housing shelters that specialize in patients with brain injury or other cognitive/mental problems with appropriate clinical supervision;

- education in the shelter system re: persons w/ TBI; wrap around care targeted at managing TBI: physician, PT, OT, SLP, medications, transportation, etc.

Recommendations to better meet the needs of older persons (>50 years of age) with TBI included:

- housing/accessible housing; group homes that provide care for TBI only
- more adult day programs for TBI pts. (and better coverage from insurance);
- community education at doctor's offices, community centers, etc. especially re: falls;
- more employment opportunities;
- adult day care and skilled nursing facilities with a unit that can care for the cognitive/behavioral issues related to TBI -- allowing for APPROPRIATE restraint use;
- Medicaid should cover therapy at home and in a nursing home.

Recommendations to better meet the needs of young adults with TBI included:

- education;
- supervised housing for TBI patient population;
- more supervised and structured programs for clients with h/o TBI; also, support groups;
- increased vocational rehab services;
- training programs geared toward persons with TBI and waiver program;
- residential brain injury program; post-rehab/maintenance day program that specializes in TBI patients so the young do not end up in a nursing facility with patients 30-40+ years their senior and with appropriate clinical supervision/management for this population; residential brain injury programs for patients who are high level physically, but with long-term/severe cognitive and behavioral problems such that they require 24 hour supervision; improved coverage of home health aids/PCAs to allow for some of these people to get home (even if family must work);
- Group homes that provide care for TBI only (not MR or MI) - covered by Medicaid; accessible housing; day habilitation programs; Medicaid should cover therapy at home and in a nursing home.

Recommendations to better meet the needs of school-age children with TBI included:

- education and life skills training;
- more education in the schools regarding TBI for staff and students;
- community education in schools, community centers, etc. especially re: prevention (helmet use, etc); also ed. schools on pts' needs upon return to school;
- early identification and prescriptive services to meet their individual needs;
- increased partnering with clinicians who deal with TBI and the public school system to allow for a safe/effective transition back to school; this will require some degree of reimbursement for this service to the clinicians due to time constraints of current practice.

What is working about the current system of supports?

- the overall services the center provided is a good support for TBI consumer;
- the TBI support groups that are in effect;
- not sure;

- good transportation system (Metro Access), although frequently they are late bringing patients to their appointments;
- Turn around time for getting Medicaid; personal care aide services via Medicaid (would like to see hours increased though)

TBI Program Evaluation

The evaluation of the Traumatic Brain Injury (TBI) program was designed to document the program's implementation and to assess the extent to which the program goals and objectives are achieved. In Year 1 the evaluation documented the activities conducted in three of the four core components of the TBI Program: 1) the re-establishment of the District of Columbia TBI Advisory Committee to provide guidance and support for the program; 2) the design and development of Needs and Resource Assessment Survey (NRAS) tools, one for homeless persons, and one for homeless service providers; and 3) the process of administration of the NRAS tools. The fourth core component, development of a District of Columbia State Action Plan to integrate informal systems of support with formal systems of care, was included among Year 2 evaluation activities.

The evaluation involved the collection of process data including review of TBI program documents, observations of Advisory Committee activities, and monitoring of data collection activities. The program documents that were reviewed included: 1) the original application submitted to the Federal Health Resources and Services Administration (HRSA), the TBI program workplan, and all reports submitted to HRSA documenting the TBI grant activities; 2) drafts of the Advisory Committee's vision and mission statements, and definitions of members' roles and responsibilities; 3) the application and participant consent form submitted for approval to the Department of Health's Institutional Review Board (IRB) in preparation for the initiation of program data collection; and 4) the several iterations of the NRAS tools.

TBI Program activities observed during Year 1 included: 1) the organizational meetings of the TBI Advisory Committee; 2) the scheduled meetings and teleconferences of the Advisory Committee and HRSA site visits; 3) the program staff efforts, with the input of the Advisory Committee, to develop and refine the NRAS tools; 4) the NRAS training sessions provided for the program staff, students, and interns hired to administer the NRAS; and 5) the administration of the NRAS tools to homeless persons and to service providers.

In addition to program staff, a sub-committee of the TBI Advisory Committee was formed among members interested in working on the program evaluation. Four committee members volunteered to serve on the sub-committee, and they participated in the evaluation data collection process, as well as provided input into the plan for the Year 2 evaluation of the program.

Year 1 Evaluation Findings

The TBI program facilitator guided the process to re-establish and organize the activities of the Advisory Committee, and helped to maintain the members' involvement and focus to work collaboratively with the TBI program staff. Advisory Committee members were actively engaged reviewing and providing input into various program reports, including drafts of the IRB

application, drafts of the NRAS tools, and the required reports to HRSA. In addition, committee members also participated in the administration of the NRAS tools, as well as providing support to the program evaluation.

The development of the NRAS tools was an iterative process in which TBI program staff, Advisory Committee members, consultants, and other stakeholders were actively involved in reviewing and providing extensive comments that were then used to refine the survey instruments and the administration procedures. Refinements to the survey tools and procedures, and training on the final versions of the surveys and administration procedures occurred prior to the beginning of formal data collection.

Project staff identified 32 shelters and other facilities that provide services to homeless men and women in the District of Columbia. Of the 32 facilities serving the homeless population, staff was able to make contact with service providers at 10 of the facilities, and complete the administration of the NRAS tools at eight facilities. At the two facilities where contacts were made, one provider stated that they had no individuals with TBI, and the other provider refused to allow staff to administer the surveys.

During the pilot-testing phase, data were collected from 40 homeless men and women and direct care staff at three facilities (one shelter and two day programs). Following the pilot testing, formal data collection with the NRAS tools occurred over a 7-month period, and a total of 209 surveys were completed on homeless men and women at eight facilities (average = 29.9/month; range = 11 – 41).

Year 2 Evaluation

The goals and objectives for Year 2 of the TBI program are identified as follows:

- To continue the leadership capacity of the State TBI Advisory Committee in identifying services and accessibility to support systems for persons with TBI and their families by 4/30/10.
- To identify formal and informal systems of support in the District of Columbia for persons with TBI and their families utilizing the TBI Needs and Resource Assessment Tool by 5/30/10.
- To develop a District of Columbia Action Plan based on the TBI Needs and Resource Assessment Report for the integration of informal systems of support with formal systems of care by 08/01/10.

The evaluation for Year 2 included activities similar to those undertaken in Year 1 to monitor and document the continuation of the TBI program implementation. In addition, the evaluation also focused on the fourth core component of the program, i.e., the development of the District of Columbia State Action Plan. The evaluation process involved the collection of data through review of TBI program documents, observations of Advisory Committee activities, and monitoring of the NRAS data collection and analysis activities. The program documents

reviewed included: 1) the TBI program workplan for Year 2, and reports submitted to HRSA documenting grant activities; 2) final drafts of the NRAS tools; and 3) the questions, formats, and procedures used to conduct the key informant interviews with service providers, and a focus group with TBI survivors and family members. Observations continued of the Advisory Committee meetings and teleconferences and the administration and validation of the NRAS tools.

Year 2 Evaluation Findings

The leadership capacity of the State TBI Advisory Committee was increased during the year with the addition of four new members; three government representatives and one consumer. Of the total of 18 Advisory Committee members six (33%) are representatives of the District and Federal Governments, seven (39%) are representatives of the service provider community, four (22%) are either TBI survivors themselves or a family member of a survivor, and one member is a representative of a TBI advocacy organization. The program has achieved the goal to ensure that at least 25% of Advisory Committee members are representative of persons with TBI, their families, and service providers. However, an effort to identify and recruit members who are representative of the homeless community is continuing. Program staff is soliciting recommendations of possible new members from current committee members; Department of Health and other government personnel, including HRSA; and service providers and advocacy groups.

Three of the members who are TBI survivors and the one family member were the most actively involved in the data collection for the program. For example, the family member participated in the administration of the NRAS at a homeless shelter, and also developed the questions used during the focus group with TBI survivors, caregivers, and family members of survivors. In addition, one Advisory Committee member who is also a TBI survivor served as the facilitator for the focus group.

Data to support the program's goal to identify formal and informal systems of support in the District of Columbia for persons with TBI and their families were gathered through the administration of the NRAS tools, the online survey of key informants through the SurveyMonkey® tool, and the focus group interview with survivors and families. The evaluation documented the use of these data collection methods, and validated the resulting data that will provide the basis for the TBI State Action Plan. The development of the State Action Plan currently is in process. The Advisory Committee members have been brought into the process and have begun to define the parameters for the content of the plan. Over the next several months the Advisory Committee will be engaged in reviewing all of the program data, making recommendations to address the identified gaps in the service system, and developing strategies for integrating informal systems of support with formal systems of care for the District's TBI population.

Evaluation Challenges and Lessons Learned

During the course of program implementation there have been a number of challenges encountered for the Advisory Committee and with the data collection processes. One of the

greatest challenges to the program and consequently to the evaluation is the fact that Advisory Committee attendance tended to be sporadic. Although the teleconferences tended to garner more participation by Committee members than did the face-to-face meetings at the Department of Health, overall member attendance tended to be low given the number listed on the membership roster. For example, while there are some individuals listed on the membership roster who never participated on the committee, some of these members did send staff to represent them, but most did not. However, the program staff worked to ensure that minutes were provided for the committee meetings and teleconferences in an effort to keep all members fully informed of program activities.

As a strategy to get more consistent involvement of Advisory Committee members, a standard procedure might be to have program staff send meeting reminders via e-mail to committee members a week before a scheduled meeting or teleconference, and request that the members RSVP their attendance. A few days before the scheduled meeting/teleconference, if a member has not responded, then program staff can follow-up with them by phone. This somewhat aggressive approach might help to boost attendance, and also provide information about the circumstances that prevent a member's consistent attendance.

It also may be helpful if staff identify aspects of program tasks that need to be completed, and personally invite Advisory Committee members to work with the program staff to undertake them. For example, staff was able to enlist the help of committee members to develop the questions for the online survey and to facilitate the focus group. Similarly, there are tasks related to the development of the State Action Plan that committee members who have not been actively involved might undertake, and then report on their progress at the meetings. The reporting would not necessarily require that they be present at the meetings, but the fact of their involvement and the outcomes of their work would be made known and available at the meetings.

The administrations of the NRAS tools did not always proceed as envisioned or according to plan. The conditions under which the NRAS tools were administered sometimes were chaotic or inappropriate due to the physical set-up of the homeless facilities or location of the data collection site. Appropriate logistics and data collection sites are critical to the collection of reliable data. In most instances, these factors were suitable. However, at some facilities the NRAS was administered in the same locations where individuals who were not being interviewed were walking around and talking and could hear the comments of the persons being interviewed. While these circumstances clearly were not ideal, staff was able to accommodate to the conditions as well as learn what conditions are most suitable for the data collection requirements.

The program staff originally intended to provide incentives, in the form of gift cards, to all participants who were determined to have possibly suffered a traumatic brain injury and completed the entire survey process. However, in an effort to reduce the possibility of individuals admitting to a brain injury merely to receive the incentive, the staff decided to provide incentives to all respondents, even those who those who did not meet the criteria for the full assessment. In addition, the program provided a variety of incentives for the participants, (i.e., gift cards for Safeway, CVS, and Subway), and the selection preferences of the participants

were equally varied. This fact demonstrated that it was important not to assume that one size fits all.

The program originally planned to conduct three focus groups; one with state and private agencies, one with service providers, and one with individuals with TBI and their families. The program staff requested that each Advisory Committee member and the agencies they represented work with the program staff in formulating the focus groups, coordinating logistics and recruiting the participants. However, the timeframe for this activity was too limited to achieve this objective, and an alternate plan was adopted in which the SurveyMonkey® procedure was to substitute for the state and private agencies and service provider focus groups. This change in procedure yielded a degree of information that may not have been possible if the change had not been made.

In addition, the focus group with the TBI survivors and families that was facilitated by a TBI survivor garnered a high degree of participation and input from the group participants. Therefore, in future efforts it will be important to consider the use of individuals to conduct the data collection who are similar to those from whom the data are being collected.

Next Steps:

- Introduce of new project facilitator to the Advisory Committee, Senkuta Riverson, MPH, who joins the project as of July 1, 2010;
- Elect Advisory Committee Chairs (Chairperson and Co-Chair);
- Distribute June Report for discussion and review findings to identify priorities and strategies for the development of the State Action Plan.
- Finalize the TBI website with inclusion the TBI fact Sheet and Resource Directory
- Continue to work with Amy Horn Groenendaal of TBITAC for technical assistance in the development of the Action Plan and sustainability activities.
- Develop the TBI State Action Plan for the District of Columbia.