



Brain Injury in the Homeless Community: Where Do We Go from Here

Summary of a dialogue held on October 8, 2015 intended to create ideas for more effective and sustainable approaches to the identification and support of people who are homeless and have brain injuries.

Introduction

The Minnesota Brain Injury Alliance invited representatives from a wide range of service providers serving the homeless as well as homeless individuals with brain injuries to participate in a half-day discussion intended to identify specific ways the Alliance could build stronger connections to the homeless community. The discussion, facilitated by senior Wilder Research consultant, covered a wide range of topics including experiences in recognizing and responding to brain injury, stigma and misunderstandings associated with this type of injury, supports and services available now, and ideas about what supports might best serve this population in the future. The information from this dialogue will be used by the Alliance to plan for outreach and intervention efforts that can best meet the diverse range of needs among those who have suffered traumatic brain injuries.

Participants

In addition to the session facilitator, a total of 24 individuals participated in the three and one-half hour discussion held at the headquarters of the Minnesota Brain Injury Alliance (MNBIA). The discussion included one brief break in the morning and a noontime break for lunch.

Eight participants were employees of the Minnesota Brain Injury Alliance, two were individuals who had sustained brain injuries themselves and also experienced homelessness, and the remaining 14 were recruited from a wide array of human service organizations. These included nonprofit providers working as advocates for homeless adults, shelter services staff, workforce development specialists, healthcare providers, ministerial staff, outreach workers, and a representative payee working with clients who had sustained brain injuries and who were receiving clients Social Security benefits. Participant responsibilities within their respective organizations ranged from directors and managers to unit supervisors and line staff. In addition, some served in specialist roles related to education and outreach. One participant was a volunteer within her organization. The majority of participants had from 1 to 5 years of experience in their current role, although, six people had been in their current role for 15 years or more. With few exceptions, the vast majority of participants had at least some direct experience in working with homeless individuals who had experienced some form of traumatic brain injury.

When asked about their goals for the discussion, one comment summed up the sentiments of the majority of participants. That is:

“To generate ideas to better serve individuals with brain injury who are experiencing homelessness.”

Within this general goal, some hoped to come away with a specific protocol of actions steps that would include more training as well as an expanded knowledge of resources which might include more face-to-face connections with brain injury specialists and advocates.

Prevalence

Every three years, Wilder Research conducts a statewide study of people who are homeless or living in temporary housing programs. The study provides point-in-time estimates of the homeless population and a description of their characteristics based on face-to-face interviews with homeless individuals and a shelter census completed by shelter providers. The interview asks a series of questions that aim to identify individuals who have likely suffered a traumatic brain injury (TBI). The information below is from Wilder's 2012 Statewide Homeless Study.

Prevalence of TBI in the homeless community

- In 2012, 34% of Minnesota's homeless adults had a history suggestive of TBI or had been told by a doctor or nurse that they had a TBI.
- The rate of TBI was highest among homeless adults residing in unsheltered settings (44%) and battered women's shelters (45%).
- The rate of TBI is higher among homeless adult males (36%) than it is among homeless adult females (32%).
- 43% of homeless American Indian adults have a TBI. This is higher than the rate of TBI among any other racial group, with the exception of multi-racial homeless adults (also 43%).

Health concerns among homeless adults with TBI

- 76% of homeless adults with a TBI also have a significant mental illness, such as major depression, bipolar disorder, personality disorder, schizophrenia, or other paranoid or delusional disorders.
- 65% of homeless adults with a TBI also have another chronic health condition, such as high blood pressure or other heart or circulatory problems, asthma or other respiratory problems, and diabetes.
- 30% of homeless adults with a TBI also have a substance abuse disorder, such as alcohol abuse or drug abuse disorder.

Discussion summary

1. What experiences have you had in recognizing brain injury where you work? Is it hard to recognize? What factors complicate this?

The main complicating factor in recognizing brain injury is the constellation of other issues that participants find when dealing with clients. Many participants find that clients with brain injuries are coming in with other coexisting concerns, such as homelessness, substance abuse, and mental health issues. These concerns are likely to take priority over brain injury. As a shelter manager mentioned, this issue also emerges with medical diagnoses of brain injury:

“If someone is coming in with several factors, they are going to identify the top one first. A traumatic brain injury is probably last on the list to be diagnosed and treated.”

Another complication is a lack of formal diagnosis for incoming clients. For some participants, not having a diagnosis must be secondary to other considerations:

“No matter what somebody presents – chemical dependency, brain injury, dementia – we have to figure out whether they are able to stay there and be safe around others, staff, themselves... It’s not a top priority to diagnose somebody. That’s not our role.”

Clients often do not acknowledge their brain injury or use those terms to describe their situation. Participants noted that clients will deny that they have a brain injury but share that they have had multiple concussions or symptoms that are consistent with brain injury:

“We ask at intake, and they say no, but then when you start talking about their history it becomes apparent that they probably do [have a brain injury].”

“They’ll answer no, but if I engage a conversation around it, they’ll say they were always getting concussions and being knocked unconscious.”

Part of clients’ refusal to discuss or acknowledge brain injury may be due to the stigma surrounding brain injury; as one support services participant noted, this stigma keeps clients from addressing the injury:

“In talking with them they can’t address their TBI in an employment situation because of the stigma. Working with them, there is a brain injury, there is something, but they aren’t willing to talk about that or address that.”

Another complicating factor is that many organizations rely on volunteers and interns for help, which requires a considerable amount of continuing training and education to handle potential crises and ongoing needs. As one participant noted,

“We used to have hired employees at the desk – they are now volunteers... It’s constantly a teaching and an educating and a learning situation that is difficult.”

2. Are there misunderstandings or preconceived assumptions about brain injury that make this particular problem more difficult to deal with other than physical or mental health problems?

Participants noted that a lack of understanding within organizations around brain injuries, as noted by one outreach specialist:

“When I’m working with folks with traumatic brain injuries, I feel skilled in mental health referrals, housing referrals, and substance abuse, but I feel a huge lack of knowledge with brain injury.”

Another barrier that participants pointed out was that the symptoms and complications of the brain injury itself can pose significant barriers for delivering services to clients. Memory issues, particularly short-term memory loss and confabulation, were identified in particular. Several participants noted the complexity of providing services to clients who did not remember appointments:

“They may miss an appointment, and then show up the next day and say they are ready to meet. For us to be flexible, that is challenging for us.”

“If they miss three [medical appointments], they won’t see them again. It’s a short term memory problem, why do that to them?”

Other participants noted that memory loss also caused issues with clients who did not remember what services they wanted, what rules were in place, when programs took place, or when they needed to pay for necessities:

“Memory issues are a big concern. We provide the same services every day on site. Many visitors don’t remember that we have laundry every day. It’s really training the staff to have the understanding that people don’t remember.”

“We will often have folks get in trouble with shelter staff because they don’t remember rules, where they are allowed to be, what times things happen.”

“Some of the questions that are asked – what services do you want? They have no idea. With short term memory loss, that is difficult to remember.”

“Most of my clients are housed, but my TBI clients are this close to eviction because they forget to pay their bills.”

Other brain injury symptoms can create barriers as well. Participants mentioned issues that arise when clients have unexpected outbursts of anger, say things that seem inappropriate, or behave in irrational ways. One outreach specialist noted how assumptions around choice, and how people choose to behave, could exacerbate issues with clients with brain injuries:

“Choice is a tool – we assume choice and options – but that tool can be injured in a brain injury.”

Part of this barrier can be attributed to the invisibility of brain injury-related issues. As one participant commented, this invisibility can affect external perceptions of clients with brain injuries:

“When people have a brain injury, it’s not believed because you can’t see it. People think they are using it as an excuse.”

Participants also noted difficulties with navigating systems and procedures that are confusing and overwhelming. One participant commented on how difficult it is to navigate processes, even for clients who do not have brain injuries:

“Trying to navigate the county process and the Social Security processes, for someone who doesn’t have a brain injury, it is overwhelming.”

“When I can follow up with someone, just having time to walk them through that process is overwhelming... They can’t even organize their thoughts to call get a neuropsychological evaluation.”

Participants mentioned that the county itself is another pressing barrier to getting services. Some participants commented that certain services will not work with clients with traumatic brain injuries; another noted an instance where a county representative denied a waiver for services because the client in question was homeless. One participant noted how the complexity of accessing services can prevent a client with a brain injury getting the assessments they need to access those services, leading to, and sometimes intensifying issues around homelessness:

“People with mental illness don’t want to stay in shelter because it is too much to handle. If they aren’t in shelter, the county won’t do a CADI assessment. If they are homeless, they aren’t using institutional money, they aren’t a priority, the county will do an assessment but they will likely get denied. They can’t stay in shelter, so they stay outside which exacerbates symptoms.”

Another barrier to service, according to participants, lies in the high turnover of support positions, leading to a lack of education or general knowledge:

“A lot of the people at the county work with many different types of people. The training they receive in a high turnover position may be inadequate. The gate keepers may have misinformation, so we are continually educating staff who have so much power, but yet very little understanding.”

Another participant mentioned a higher bar for clients to receive services, even if an assessment is approved:

“If I can get people in to have neurological testing, it’s denied because the traumatic brain injury is too distant. It makes it hard to have a solid report. I’ve been bumping up to that more over the last couple years.”

3. Is the problem of brain injury more difficult to address in some cultural groups in than in others?

Participants discussed three main difficulties in addressing brain injuries in non-dominant cultural groups. The first difficulty is a cultural barrier, which encompasses more than language, as explained by one participant:

“I think finding appropriate care for the population we served in general is very difficult. When we are looking at trying to find someone from the same culture, is really difficult. Even an interpreter is not the same as seeing someone who looks like you and understands your culture.”

The second difficulty is the nuance of language, as noted by a Hmong participant:

“For the Hmong population, it is difficult to talk about the brain in our culture because of the language barrier. We don’t have words for brain injury, mental health, asthma, etc. When talking about brain injury we have to describe the symptoms. When you are talking with an interpreter who isn’t knowledgeable about brain injury, they may not be able to communicate what is being said.”

The third difficulty is working with cultures that either do not follow Western medicine or are otherwise protective of members of their cultural community:

“We have a really difficult time reaching out to some cultures because they are really protective of their own. Just getting in and understanding their culture, that’s really hard for us.”

4. What challenges or barriers have you faced in trying to respond to the needs of someone with a suspected brain injury? Do shelter circumstances make this more difficult? How? (What helps?)

Participants noted that a lack of support – either from family or from an advocate – was a significant challenge in responding to client needs. Several participants noted the power of community and building relationships between organizations in order to help clients with coexisting conditions receive support and care for all of them:

“We’ve found that people who have a one on one relationship with an advocate, whether it’s family or someone else, will have better success at achieving their goals.”

“When an advocate or someone who knows the person is able to speak up, we can approve the person for a waiver because they can get at the actual problem.”

“The relationships are key for making things successful. We have to have the resources on site... We have all of these components on site and build their relationships within the confines of the building.”

“Communication from whoever is coming to the shelters and bringing the client to have a face-to-face introduction can really help.”

Another participant mentioned that having the time and staff to strengthen relationships with clients makes a difference:

“If they need a ride to an eye doctor, we drive them there. It’s an extended warm handoff. The ability to go out into the community and spend time with them, that makes all the difference.”

A few participants also noted that having flexible scheduling is helpful for clients who may forget appointments or encounter other challenges as a result of their brain injury.

Some participants mentioned that funding is a barrier to responding to needs, particularly funding for client advocates:

“We need to fund people to advocate and provide lots of time. There are services available but they need someone to help access them.”

Time is another challenge for those trying to secure services for clients. One participant shared a story about a client whose mother’s relentless contact secured services:

“What made it happen [for one client] was his mom. I have 200 clients and she had one.”

A few participants also noted that earning and keeping client trust was a challenge.

“For the people I work with, trust is an issue. They have been let down multiple times. You might have to meet with people 10 or 15 times.”

“When I went out to various centers, I met with three different people, all of them adamantly refused to give me a release of information so that this person can connect... It’s a struggle when we go into shelters, we don’t know who they have. They won’t or can’t tell us.”

One participant mentioned that this hesitance may be because clients hear from too many different people:

“The people who follow up with the referrals are different from those who are going into shelters. [Outreach] might make a connection, but then one of the referral folks calls and they don’t know who you are. Trust is a big issue.”

In response, one participant shared that they try to make this connection as smooth as possible:

“What I do – I would like to think I am very aware of resources out there – I try to write down what they should do if someone doesn’t call right away. I tell them who will call them.”

Participants also noted the challenge of time and effort to get clients connected to services. Two participants shared stories of how difficult it was, and long it took, for a client to get services:

“We know it can work, but we know we have lots of challenges and barriers that cause the success story not to happen... [It was] probably about a yearlong process.”

“It took over 50 phone calls and two years to help an individual qualify for a waiver.”

5. What else can MNBIA do? What are some next steps?

One suggestion from participants was for MNBIA to help connect clients with brain injuries to resources in various ways, including warm handoffs and finding clients where they are (rather than forcing them to find services elsewhere):

“I would suggest that MNBIA comes out more to where the people are because we’ve already identified how hard it is for people with traumatic brain injuries to keep appointments and make connections between professionals. My goal is to bring more of the mental health professionals into the shelter because that’s where the sheltered people are comfortable. We know that when we do straight referrals, half the time it doesn’t happen.”

“The greatest success you have is when you have the actual professions in the building so that people can access what they need right there.”

These participants suggested that MNBIA identify persons on their staff who are experts in brain injury and encourage them to connect with a variety of service providers. Through these efforts it would be possible to create an infrastructure of support between providers, and build rapport and trust with volunteers and staff at shelters. Participants also suggested that MNBIA work to recognize and remove barriers between service databases, such as the MNBIA and HMIS databases.

Another participant suggested that service providers receive education on available resources and eligibility for those resources to better understand for themselves and to more effectively guide clients.

Several topics were suggested for the MNBIA to provide training for those who serve the homeless. These topics include: brain injury basics (still needed for some volunteers); available resources for clients; how to connect with healthcare for the homeless; the continuum of care of services provided and outcomes for clients; and how to communicate effectively with people with brain injuries.

For clients or others experiencing homelessness, participants suggested that MNBIA help to provide information on services and how to connect with MNBIA, and to make these presentations creative and interactive. Other suggestions included holding a one-half day conference in Minneapolis or St. Paul to reach consumers and providers hosted by the MNBIA Resource Facilitators and establishing connections with the St. Paul Area Coalition for the Homeless and the Metro-wide Engagement for Shelter and Housing (MESH), two groups not represented in today's conversation.

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