

April 6, 2023



Brain Injury Services Project: In-Person Lived Experience Focus Group at the Mill House Club House

Meeting Summary

Meeting: Brain Injury Services Project: In-Person Lived Experience Focus Group at the Mill House Club House

Date/Time: April 6, 2023, 1:00pm – 2:00pm

Location: The Mill House Club House for Individuals with Brain Injury, Richmond, VA

Attendees:

- Members and staff of the Mill House Club House
- Meeting Facilitators:
 - Kshitija Karmarkar, Department of Medical Assistance Services
 - Christiane Miller, Department for Aging and Rehabilitative Services
 - David DeBiasi, Brain Injury Association of Virginia

Key Discussion Points

The meeting began with

1. introductions of the attendees, including the club house members and staff, and the meeting facilitators.
2. A review of the key legislation that is guiding a new program. The main initiatives from the legislation include the implementation of targeted case management for the traumatic brain injury population in Virginia and the study and design of a waiver and neurobehavioral unit for Virginians with brain injury (BI).

The focus group was geared towards individuals with BI attending the Mill House.

The purpose of the session was to collect feedback around services needs for individuals with BI.

Based on the feedback gathered, the facilitators documented the following key themes that will inform the proposed BI services program by the Department of Medical Assistance Services (DMAS) for presenting the finalized program to the General Assembly for approval.

April 6, 2023



Brain Injury Services Project: In-Person Lived Experience Focus Group at the Mill House Club House

Specific Questions posed by the facilitators to the members of the Club House:

1. What would help you live more independently? What services could our agencies provide to you that would help you live more independently?

Many expressed agreement with the following statements:

More supportive housing facilities.

Independent housing.

More transportation to healthcare services, and for getting to places like The Mill House, more places like Mill House that are closer by to where people live.

Increased financial assistance for housing.

More programs like the Mill House – a place to gather with peers, make friends, the support of staff, a place to learn new skills.

Individual expressions included:

It would be easier to live independently if more people understand and accepted her. Without acceptance and understanding it is difficult to have a support network.

More awareness of brain injury services by human service and health care worker's so they can refer brain injury survivors to places like The Mill House.

Living in my own apartment – currently, living at her brother's house. The person expressed she would need an aide to help her be able to live independently in the apartment.

As far as independent living goes, there need to be safer facilities – accessibility wise – thresholds could be tripping hazards. Preferably no doors, and doorframes with no thresholds.

A road map to understand and navigate the healthcare system.

Brain Injury Services Project: In-Person Lived Experience Focus Group at the Mill House Club House

2. What supports would help you get a job or if you have a job what supports would help you keep it?

An individual expressed that the employer needs to be able to understand his strengths and not just his limitations. He expressed that was the reason why he lost his last job.

Another person, who is a young mother, expressed that she would like for people to understand what it is like to live with a brain injury, and at least show a little grace. Others expressed agreement.

Others expressed they would like to work, but they are concerned that if they go to work they would lose their disability benefits that they need and find very helpful. Others expressed agreement that disability insurance putting a limit on how much you can work is a barrier.

Someone added: help/support from someone at workplace, if they have a job, to help keep the job, by providing necessary support to the individual and training to the employer or coworkers, so their job is safeguarded.

3. What support could our agencies offer to support having a healthy social life?

Being active on Social Media. Others agreed. One young woman expressed getting off social media was actually helpful for her. She felt more at ease making in-person connections rather than through social media after her brain injury. In response, it was suggested training could help people learn how to get on and use social media, and how to not get scammed on social media.

Strong agreement on more places like the Mill House.

Transportation to where people gather. Many agreed. One person noted, transportation alone is not going to solve the problem. It needs to be reliable so you can get to where you're going on time.

What would help us overall, is a good understanding and social acceptance of people with brain injury. People should not be judging us as unintelligent or ignorant. Social awareness about brain injury would help. The person suggested a movie about a brain injury survivor might raise public understanding. The group facilitator encouraged her to write the script for that movie, or a book, or least a letter to the editor.

One individual expressed need for funding for advocacy efforts to remove the stigmas around having a brain injury or about people with brain injury.

April 6, 2023



Brain Injury Services Project: In-Person Lived Experience Focus Group at the Mill House Club House

One individual shared that his brain injury made him feel invisible. He expressed that he has experienced people mistreating, misjudging him. He said because when he got his brain injury there was no awareness. It took for boxers, football players, people that ride the bulls, etc., to start getting traumatic brain injuries (sports injuries); it took for them to start getting the media/attention, for people to start realizing and starting to understand how people with brain injury function. People are quick to be judgmental and to label others if they don't understand them (like he's crazy or he doesn't make any sense) instead of trying to understand them, their story. And once you have that "crazy" label on you, everybody's going to stay away from you. He worked at McDonald's and gave an example that he helped a person who was struggling to explain themselves to a cashier. Their transportation bus reportedly had dropped them off after a request to use a bathroom and then left. The individual didn't know what to do and employees were dismissive or ready to call the police. He calmed the person down and helped him call his mother. People don't wait to think the situation through they don't have the patience. That's why you won't see us walking around freely. We are in a house or in secluded settings. If you're walking down Broad Street, someone has a spasmodic outburst, you're going to think, "oh maybe he's on drugs?" But you're not going to give it a second thought that maybe he is having some problem, maybe he has a genuine issue and something is wrong.

There was general agreement that support of/from case managers, advocates, aides was essential. Interest was shown in receiving support from a peer mentor or a professional with a disability

One individual disagreed with having peer support- he said we could do it by ourselves. Push ourselves to be better and better.

Another agreed with having professional peers, or job coaches, who had a disability or a brain injury themselves.

Someone gave an example of a person at Mill House doing that in the past. But that individual who wanted to offer himself in that role was having trouble getting referrals.

Help the Mill House expand, make this whole building for that purpose – make this a bigger facility (that can serve more individuals with brain injury).

Coming to Mill House, is a beautiful experience, you can sit and talk with others and enjoy our time together.

April 6, 2023



Brain Injury Services Project: In-Person Lived Experience Focus Group at the Mill House Club House

4. What would help you further participate in your home and communities?

More opportunities.

More people understanding what is going on for an individual who has had a BI.

Equal opportunities. Background checks in job applications (can be a hurdle). There is a lot of stereotyping and bias that goes around with respect to providing equal opportunities to those with brain injury. If you check the box that you have a disability, then they don't consider your application any further irrespective of what you can do or have done.

A person gave an example of a friend who chose not to disclose. The person's point was that if you disclose you may not get a job and if you don't disclose you may not get accommodations.

The individual new to Virginia said that he knew he had found his place in the first three or four days of coming to The Mill House. Until then he believed he was the only one going through this. "I felt like an outcast. Now I feel like I belong here. Now that my mom works at brain injury facility, she now sees what I was going through in my younger days in childhood, those were genuine difficulties, everything that I was saying to her, everything that I was showing her that I was going through; from her dealing with me all my life, she understood it more only after she realized there are a lot more people who experience these same type of difficulties. At the Mill House we don't feel like I am better than you, or you are better than me. We all feel the same. We all feel accepting of each other and we all feel like we are part of something together. We don't feel ashamed; we don't feel weird".

An individual with aphasia said people here understand me.

There was a general discussion about other benefits of the Mill House. Comments included:

They teach you stuff. Like how to cook.

We have a variety of tasks that we volunteer for throughout the course of the day – we have our unit coordinator to help us, support us, and answer any questions we might have. When we go home we have a sense of accomplishment that we did something. I am of the opinion that everything in life is contagious including this feeling helping improve our quality of life. Keep or skills, and develop new skills. One of the coordinators – it's Shelby, one before her was Katie she actually helped me find a job, she attended my job interview with me, almost as a facilitator between the management and me applying for the job, great support

I feel comfortable to speak my mind to, like this is my family.

April 6, 2023



Brain Injury Services Project: In-Person Lived Experience Focus Group at the Mill House Club House

They teach how to be an advocate. Going to the general assembly to speak to legislator and letter writing – lots of letter writing,

An individual noted that advocacy is needed for safe driving. She shared that they had their head injury in 1997 when she was an adolescent driving her first car. She ran off road on a turn, hit a tree head on, and then shared the different programs that she was in. She said, people like us – we need to let people know that you need to stop texting while driving, or doing anything else while driving, especially for people who are getting behind the wheel for the first time.

Another agreed and said we could really prevent a lot of bad things from happening, because people “would see us and say I don’t want this to happen to me. Maybe they’d be stay safe”.

NOTE: A response consistent across all questions was that The Mill House is an invaluable resource.