

March 31, 2023



Brain Injury Services: Lived Experience Focus Group

Independence House

Meeting Summary

Meeting: Brain Injury Services: Lived Experience Focus Group

Date/Time: March 31, 2023, 8:30 am – 9:45 am

Location: In Person @ Independence House, Richmond, VA

Attendees:

- Focus Group Members: Five men who reside at Independence House
- Outreach: Virginia Supportive Housing/Brain Injury Services
- Focus Group Facilitators:
 - Kshitija Karmarkar, Brain Injury Services Program Advisor, Department of Medical Assistance Services
 - Christiane Miller, Director of Brain Injury Services, Department for Aging and Rehabilitative Services (DARS)
 - David DeBiasi, Director, Brain Injury Association of Virginia

Key Discussion Points

I. Background and Purpose

- a. The meeting began with an explanation that Virginia is looking at expanding services for individuals with brain injury through Medicaid. Participants were asked for their input based on their unique living situation (individual rooms with a shared common space, kitchen, and bathrooms) and their previous experiences.
- b. The focus group was geared towards individuals in Virginia with a lived experience of brain injury. The purpose of the session was to collect feedback around waiver services. Based on the feedback gathered, the facilitators will document key themes and share the input back to the Department of Medical Assistance Services (DMAS). DMAS will incorporate the feedback into the proposed program and present the program to the General Assembly for approval.

II. General Feedback and Suggestions

Themes that emerged from the focus group.

- a. Living with brain injury is difficult and all the participants expressed the desire to have people in their lives that understand what they are experiencing. This includes family, friends, employers, staff.
- b. Safety was a big concern among all the participants. The idea of living alone did not feel safe for many because of memory issues or fear of being taken advantage of by others.

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- c. Comments from the focus group participants made it clear that staff providing brain injury services must have training to assure they understand brain injury. Their input also indicated training and support for family and other supports would be beneficial.

III. Discussion Question 1: What would help you live more independently?

- a. Better medical care. One example noted is dealing with a seizure disorder.
- b. A personal care aide and/or someone who could help with reminders for appointments and medications because most of them deal with problems with memory. Someone who might provide assistance several times a week.
- c. Assistive Technology to help with medication management and other skills.
- d. Mental Health Counseling was noted as being beneficial for many of those present and suggested for one individual struggling with the loss of family and relationships.
- e. A few of the participants expressed the need for substance abuse treatment with providers who understand brain injury.
- f. Supportive staff like their current staff person who helps them access benefits and services, manage schedules, try new things, and is available to help them handle whatever challenges may emerge.
- g. Pets. One person has a cat and reported this has made a significant difference in his life. She helps keep him calm and relaxed and he enjoys her company. Several others expressed interest in a pet or that they enjoyed their housemate's cat.
- h. Peer Support was identified as a support they would be interested in having because the peer would know/understand their experiences and challenges as a result of having a brain injury.
- i. In many of their responses, the participants noted the relationships and supports they provide each other with both actions to help each other and emotional support. They have created a community/family with each other.

IV. Discussion Question 2: If you'd like a job - What would help you find one? /If you have a job, what would help you keep it?

- a. Individuals had varied experiences with DARS vocational rehabilitation services (DARS VR). One individual found a job and had on the job support through DARS VR. One individual was not successful in maintaining a job and felt that his VR Counselor and employers did not understand the impacts of his brain injury.
- b. One individual was able to return to a job he had before his injury, but this was because his employer was willing to make accommodations for him, including a reduced schedule and allowing him to work at night which is less stressful for him.
- c. Job support in small groups was of interest to several people because they would be with other people with similar challenges who would understand and could provide encouragement/support.

V. Discussion Question 3: How do you have a satisfying social life? /What services might support that?

- a. Affordable, safe, trustworthy transportation to get to places they like to go together like church to play pool, or the park.

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- b. Adaptive sports opportunities like Sportable and Camp Bruce McCoy. Those that had been to Camp Bruce McCoy (a camp specifically for people with brain injury) noted that it was nice to go to a place where you could be yourself and with others who understood your experiences. Plus, it is fun.

VI. Discussion Question 4: What would further help you participate in your home and community?

- a. Many of the participants were interested in learning more about using computers for work and for recreation. They also expressed interest in learning for learning's sake is valuable.

For more information about the lived experience focus group meeting please refer to the presentation slides which can be found at <https://www.dmas.virginia.gov/for-providers/long-term-care/programs-and-initiatives/brain-injury-services/>.