

March 10, 2023



## Brain Injury Services: Lived Experience Focus Group

### Meeting Summary

Meeting: Brain Injury Services: Lived Experience Focus Group

Date/Time: March 10, 2023, 1:00pm – 2:30pm

Location: Zoom

Attendees:

- Focus Group Members: Andrew Davie, Anne ?, Bronwyn Stokes, Beacon House, Geoffrey ?, Jeffrey Gilbert, Katelyn Oldrige, Melissa Earley, No Limits, Shasmin Asbury, Shunda Smith, Toni P?, Trey ?
- State Staff (facilitators): Ann Bevan, Chris Miller, Kay Karmarker
- Guidehouse Staff (facilitators): Danielle Studenberg, Elizabeth Barabas, Linda Wegerson, Roya Lackey, Sharon Hicks

### Key Discussion Points

#### I. Background and Purpose

- a. The meeting began with 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).
- b. The focus group was geared towards individuals in Virginia with a lived experience of BI. 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

- a. We received some general feedback.
  - i. This included commentary that every BI journey is unique. Therefore, services should be individualized to the needs of the person with BI to meet them where they are.
  - ii. This included concerns about social security and disability. Broadly, individuals felt that these funds were not enough to cover daily life and that they are incorrectly denied eligibility.
  - iii. This also included concerns about availability and affordability for affordable housing.
  - iv. This included frustration that they could not receive help from existing waiver because of eligibility or because services aren't covered. Individuals also noted long waiting lists for existing services.
  - v. Individuals requested help with getting a license or ID which may help with obtaining services.
  - vi. Participants noted that they appreciated the opportunity to be an advocate and share their stories.

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### III. Discussion Question 1: What might help you with living independently?

- a. Focus group members noted that it can be difficult to find a personal care attendant that is familiar with BI. Focus group members noted the fear of being alone around others and suggested that an aid would help alleviate that fear. Generally, individuals requested additional training for providers working with the BI population.
- b. Individuals requested case management services specific to BI.
- c. Focus group members requested residential services or supportive housing that are not nursing facilities, especially those with specialized training in BI.
- d. Focus group members said they are looking to have people generally helping them out.
- e. Individuals requested help with getting and keeping a job.
- f. Focus group members are seeking financial management services and legal aid.
- g. Individuals suggested environmental modifications to help with wheelchair ramps, lower counters, and other changes that would help with maintaining independence.

### IV. Discussion Question 2: What might help you with getting and keeping a job?

- a. Focus group members suggested increased access to transportation, as public transportation can be difficult and often getting somewhere requires a knowledge of each individual's skills and abilities.
- b. Individuals mentioned that training for employers on how to best work with the BI population would be helpful.
- c. Individuals noted that assistive technology could also help with getting and keeping a job.

### V. Discussion Question 3: What might help you with having a satisfying social life?

- a. Individuals mentioned that getting and keeping a job would help gain friends and have a more satisfying social life.
- b. Focus group members noted that they really appreciate having friends and places to go where people understand and take seriously the BI experience.
- c. Focus group members suggested that therapy would help figure out what elements create a satisfying social life for each person, especially in the time of COVID where social experiences look different.
- d. Individuals suggested that handicap accessible transportation and more funding for BI survivors to attend fun and appropriate places.

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

- a. Focus group member requested someone to go to with questions about their specific situation.
- b. Participants are looking for more opportunities to share their stories, but also noted that this can cause burnout because they have to discuss all of their personal issues publicly.
- c. Attendees expressed similar feelings related to the frequency at which they have to justify their need for support services, especially in cases where their challenges are less obvious to others. They noted it can be emotionally burdensome to regularly explain or defend one's difficulties to others and takes away from time spent focused on what *is* possible.

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*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/>.*