

March 10, 2023



## Brain Injury Services: Families/Caretakers Focus Group

### Meeting Summary

Meeting: Brain Injury Services: Families/Caretakers Focus Group

Date/Time: March 10, 2023, 11:00am – 12:30pm

Location: Zoom

Attendees:

- Focus Group Members: Debra Halloway, Elizabeth Horn, Jillian Gomez (and her daughter un-named), Bronwyn Stokes, Debbie Probst, Sharry Maddux, Regina Richardson
- 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 family members and caretakers of individuals with BI in Virginia. 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 and recovery is not always linear. Therefore, services should be individualized to the needs of the person with BI.
  - ii. This also included frustration that loved ones could not receive help from existing waiver services because they live in assisted living, because of the county they live in, or because the eligibility assessment was not reflective of capabilities. Family members also noted that getting on the waivers takes a long time.
  - iii. Families noted that the existing system can be hard to maneuver and that it can be hard to know what services are available.
  - iv. This also included recommendations that services should be accessible across the entire state, not just in specific geographies.
  - v. One family member stated that for those individuals with BI here on a visa, there is no pathway for citizenship because there is no box to check that someone has a BI.

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- vi. This also included feedback that eligibility should be beyond nursing home criteria as this would not appropriately capture all individuals with BI.

### III. Discussion Question 1: What might help your family member become more independent?

- a. Family members recommended the following services be included in the proposed categories of service:
  - i. General Assistance with Activities of Daily Living (ADLs): For some of the families, their loved ones do not need a skilled nursing facility but do require additional help on some ADLs. This is especially true in cases where the individual requires less or no physical support, but rather more cognitive support or supervision to ensure safety. For example, an individual may be able to dress themselves with physical independence but choose clothing that is inappropriate and unsafe for the weather. Or, an individual may be physically capable of cooking a meal, but may make unsafe judgments around food preparation/kitchen safety. These cases may not meet criteria to qualify for a higher level of care despite them posing significant risks to one's health and safety.
  - ii. Behavioral Supports: This could include components of Applied Behavior Analysis (ABA), such as consultations and other services. One family member noted that individuals often need an Autism diagnosis to get ABA services.
  - iii. Companion or Personal Assistance Services: These services would aid in socialization and would help individuals with BI experience more activities.
  - iv. Legal and Trustee Services: This would be specifically helpful for when individuals with BI are taken to the hospital.
  - v. Respite Care Services: This would help provide a break for family members.
  - vi. Residential Services: Family members also noted the importance of these types of services given that options for these types of services do not exist currently.
  - vii. Supported Employment Services: Family members suggested a program to assist people with BI with volunteering or employment.
  - viii. Transportation Services: "Door to Door" transportation services are necessary, not just "Curb to Curb." One family member also recommended reminders about transportation.

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

- a. Family members shared that it can be hard to find job or volunteer opportunities for loved ones that do want to work. They suggested creation of a job board or a list of employers who are open to employing those with a BI.
- b. Family members noted the importance of job skills training to help their loved ones achieve a job, including resume building and interview preparation guidance.
- c. They also suggested that employers could have education or training about BI.

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

- a. Family members noted a private company called Neighbor Force that provides companion care for a fee. They noted that it would be helpful to have these services covered.
- b. Family members suggested transportation services would aid in social supports, especially for those that need wheelchair accessible vehicles.

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- c. Family members recommended including activities for community programs outside of walking around a store or eating. Ideas like rock climbing or going on a boat would be fun activities for their loved ones.
- d. They noted that additional day programs or changing the requirements for existing day programs might aid in socialization. Existing services cannot always be used because how they are regulated or defined. For example, current day programs require at least 6 hours of services, but often those with a brain injury cannot be there for 6 hours. Another example is those individuals that may need an assistant at a day program but don't qualify for personal assistance.

### VI. Discussion Question 4: What might help you feel secure about your family member's safety?

- a. Assistive Technology: Family members would feel more confident knowing that technology was providing support. Examples include stoves that turn off after a certain amount of time or technology that monitors when people are awake, in case they are awake at odd hours. A list of available assistive technology would help support caretakers.
- b. Personal Assistance: Family members requested aids that could assist when someone goes to the hospital. One family member suggested using Smart911, a community initiative that allows a hospital access to diagnoses, a list of verbal and physical skills, and more for all hospitals.
- c. Training and Education: Family members suggested training or education for why their loved one has changed, especially in the first year after the BI. This could apply to all people that individuals with BI interact with on a regular basis. Training should include de-escalation strategies and how to deal with aggressive or verbally abusive behaviors.

### VII. Discussion Question 5: What might help you better handle the challenges and stressors related to your family member's brain injury?

- a. Family members noted that respite, personal aids, and community care would be beneficial as those services currently fall on the family to support.
- b. One family member noted that therapy for the caregivers would be helpful. Support groups have also been beneficial to family members.
- c. Family members suggested financial resources or guidance, including what items can be claimed on tax forms, because they experience a lot of financial troubles.

*For more information about the families/caretakers 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/>.*