

March 13, 2023



Brain Injury Services: Families/Caretakers Focus Group

Meeting Summary

Meeting: Brain Injury Services: Families/Caretakers Focus Group

Date/Time: March 13, 2023, 5:30pm – 7:00pm

Location: Zoom

Attendees:

- Focus Group Members: Karen I, Lorraine, Sharry Maddux
- 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. Families noted that it can often be difficult to get help for their loved one because individuals with BI may be reluctant to be evaluated.
 - ii. Families shared 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.
 - iii. This also included frustration that loved ones could not receive help from existing waiver services because they live in assisted living.
 - iv. One focus group participant suggested hosting a third focus group session for families due to sparse attendance at this session.

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. Companion and Personal Assistance Services: These services would aid in socialization and would help individuals with BI experience more activities.

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- ii. 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.
- iii. Social Networking: Family members suggested that having clubs or social networks as a place to go might help their loved one.
- iv. Supported Employment Services: Family members suggested a program to assist people with BI with volunteering or employment. This could include job training to help get and keep a job, which in turn could support emotional wellbeing.
- v. Transportation Services: “Door to Door” transportation services are necessary, not just “Curb to Curb” for individuals who may need assistance safely reaching their home due to physical and/or cognitive challenges. 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. Family members suggested that an aid would help some individuals keep a job as they could help with work skills.
- d. Family members also noted the importance of volunteering in addition to or instead of employment to give the survivor a sense of purpose and to help build their skills.
- e. Family members noted that transportation is crucial to allow individuals to get to their job.

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

- a. Family members noted an organization called Sportable that helps with socialization and making friends.
- b. They noted that jobs and volunteering opportunities may help their loved one make friends.
- c. Family members suggested transportation services would aid in social supports and that online socialization options could help overcome the transportation concerns.
- 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 BI cannot be there for 6 hours.

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 technology to help with speech problems, a geo tracker, and smart appliances. A list of available assistive technology would help support caretakers.
- b. Financial Management and Legal Aid: Focus group members noted that families often worry about the survivor’s financial future. They also noted families may need help with identifying lawyers with experience helping individual with BI and their families.

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- c. Personal Assistance: Family members requested aids that could assist with giving the individual more alone time so that they don't need to be as concerned about their loved ones' safety.

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 personal aids, reliable transportation, and reliable housing would be beneficial as those services currently fall on the family to support.
- b. One family member suggested broader availability for support groups.

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/>.