Evaluating Impact:

Measuring Outcomes of Specialized Consultative Services in the NC TBI Waiver

What is the TBI Waiver?

The **North Carolina TBI Waiver** provides support and services to individuals with traumatic brain injuries, helping them live independently in their communities. It offers access to resources like rehabilitation, personal care, and case management.

These services provide a community-based alternative to institutional care for persons who continue to require a specialty hospital or skilled nursing facility (SNF) level of care.

Goals of the TBI Waiver

- Value and support waiver beneficiaries to be fully functioning members of their community

- Promote rehabilitation; evidence-based practices and promising practices that result in real life outcomes for beneficiaries

- Offer person-centered service options to facilitate each beneficiary's ability to live in homes of their choice, have employment or engage in a purposeful day of their choice and achieve life goals

- Provide the opportunity for all beneficiaries to contribute to the development of their services

Goals of the TBI Waiver

- Provide training and support to foster the development of strong natural support networks that enable beneficiaries to be less reliant on formal support systems
- Ensure the well-being and safety of the people served
- Maximize the beneficiary’s self-determination, self-advocacy and self-sufficiency
- Increase opportunities for community integration through work, lifelong learning, recreation and socialization
- Provide quality services and improve outcomes.

Who is eligible?

The NC TBI Waiver is available to eligible individuals who sustained their TBI at or after 18 years of age, living in the Alliance Health Behavioral Health and Intellectual/Developmental Disabilities Tailored Plan catchment area.

Counties currently served by Alliance Healthcare include:

- Cumberland
- Durham
- Harnett
- Johnston
- Mecklenburg
- Orange
- Wake

Who is eligible?

TBI services are available to eligible individuals who:

- Live in one of the participating counties
- Had a severe TBI that happened on or after age 18 that
    - Is likely to continue for a long time
    - Causes major challenges to complete daily actions
    - Causes individual to need more than one type of service and supports to be more independent
- Are eligible and applied for Medicaid to receive TBI services

For a complete list of TBI services, see the “Service Definitions” section on pages 8-13 of the **Alliance TBI Waiver handbook.**

What are Specialized Consultative Services?

- **Specialized Consultation Services** provide training and help in a specialty area.
- The specialty areas include psychology, behavior intervention, speech therapy, therapeutic recreation, augmentative communication, assistive technology equipment, occupational therapy, physical therapy and nutrition.
- Family members and other paid/unpaid caregivers are trained by a certified, licensed, and/ or registered professional or qualified assistive technology professionals to carry out therapeutic interventions, increase the effectiveness of the specialized therapy, and participate in your team meetings.

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- This service is very important as it can help your family, caregivers, and paid service providers learn how to provide the right supports for you.

The need for a Caregiver Assessment

- **Up until now we have relied on anecdotal information to support our results.**
- We were tasked with measuring caregiver outcomes in a more objective way.
- To date, there have been no outcome measurement tools that assess the educational knowledge, confidence in providing care or quality of life of the caregiver or member involved in the NC TBI Waiver program.
- Allied health has objective assessment tools available to measure outcomes however, **the role of SCS with TBI waiver did not**.
- These assessments are necessary to ensure SCS therapists are providing relevant education to caregivers that will improve both member and caregiver quality of life.

Collaboration with Baylor OTD

- Innovative OT Solutions, Inc and Cognitive Tx Solutions, Inc collaborated with **Katy Alek,** who was an OTD graduate student from Baylor University for her Capstone project.
- After reviewing current research, **a caregiver "Needs Assessment" was completed,** our first step in measuring the effectiveness of the SCS education and training provided to caregivers of TBI Waiver members.
- Katy spent 14 weeks in our TBI community to help assess the needs and develop a pilot questionnaire/ assessment tool.

Why is Caregiver Education Important

- **Caregiver burden**: feelings of anxiety and depression that develop when caregiver needs are not met [1, 2].
    - negatively impacts the client-caregiver relationship, the client and caregiver's quality of life and the caregiver's ability to facilitate client participation in the community[1, 2].
- Therapeutic intervention and **caregiver education** have been shown to enhance client and caregiver quality of life [2, 3].
- Systematic measures are necessary to identify areas where additional caregiver education could better support clients with TBIs during community reintegration
    - Once needs are identified, tailored education and training provided to positively impact client and caregiver quality of life and strengthen the client-caregiver relationship

Purpose of the Capstone Project

This project aims to evaluate the effectiveness of the caregiver education our SCS services provide by

- To identify effective outcome measures that evaluate the quality of life for both clients and caregivers
- To develop a comprehensive questionnaire that identifies challenges and concerns caregivers face while supporting their client's participation in activities at home and in the community

Methods

Participants: Caregivers of clients who have a TBI were eligible for this project

- The questionnaire was trialed with 6 caregivers: 1 independently completed the questionnaire, 1 requested to complete the questionnaire via interview with the student, 3 declined to participate, and 1 did not return the questionnaire during the trial period

Instruments Used:

- Initial informal interviews with caregivers and therapists to understand needs, concerns and challenges caregivers face (part of the needs assessment)
- Subjective Caregiver Questionnaire, developed by the student, piloted with caregivers to identify caregiver concerns and areas needing additional therapist support or education

Questionnaire Design

- Qualitative, self-report caregiver questionnaire with one Likert scale to assess the difficulty of managing activities of daily
- Sections: caregiver background and experience, daily routines and activities, managing activities of daily living (Likert Scale Section), community access, socialization, client behaviors requiring additional support, caregiver concerns, and an anonymous evaluation of specialized consultative services and therapists
- **The Questionnaire:**

Results

The small sample size (N=2) limits the ability to identify overarching trends, however notable findings include:

- All areas of the Activities of Daily Living Management section were rated “Easy to Manage” except “Participating in Meaningful Activities,” which was rated as “Somewhat/Sometimes Difficult to Manage”
- One identified educational need was strategies for motivating clients to participate in the community and meaningful activities, particularly when they are unmotivated or struggling with depression

Questionnaire Benefits and Challenges

Benefits:

- Setting-specific questionnaire designed for Specialized Consultative Services and the TBI waiver program
- Open-ended questions allow for nuanced expression of caregiver concerns and needs
- Likert Scale section allows for quantitative data collection
- Comprehensive questionnaire, collecting information in many areas of caregiving

Challenges:

- Long questionnaire length can be fatiguing
- Relevancy of questions for paid staff vs unpaid family caregivers

Our Next Steps

- Caregiver and client quality of life was not assessed due to time constraints
  - Possible standardized, quantitative quality of life measures:
    - Traumatic Brain Injury Caregiver Quality of Life (TBI−CareQOL)[4]
    - Quality of Life After Brain Injury Questionnaire (QOLIBRI)[5]
    - Zarit Burden Interview[6]
- Feedback will used to adjust the questionnaire, and its implementation will help identify unmet caregiver needs our therapists can address, leading to:
  - reduced “caregiver burden”
  - stronger client-caregiver relationships
  - increased opportunities for client participation in the community
  - enhanced client and caregiver quality of life

Questions and Suggestions

We would love to hear any **feedback** you have about the questionnaire and any questionnaires/assessments you use in community health settings!

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How to get started:

To learn more, you can:

- Visit the Alliance TBI Waiver handbook
- Call Alliance Member and Recipient Services at 800-510-9132, Monday-Saturday, 7 a.m. to 6 p.m. Ask for a TBI Access Specialist.
- Join one of Alliance’s upcoming NC Traumatic Brain Injury Waiver Overview trainings

Resources:

- Application for 1915(c) HCBS Waiver - July 01, 2024

Traumatic Brain Injury (TBI) Waiver Services - Alliance Health

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