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A Report on Barriers to Community Integration of People with Traumatic Brain Injury in Ohio Nursing Facilities

EXECUTIVE SUMMARY

Disability Rights Ohio and the Ohio Brain Injury Program collaborated on a project focused on community integration for people with traumatic brain injury (TBI) living in nursing facilities in Ohio. The purpose of the project was to identify major service gaps that are barriers to people with TBI living in the community and to use the information to inform changes in state support systems so that people with TBI are more integrated into their communities.

A standard interview protocol was used to gather information from 38 persons with TBI living in nursing facilities, their caregivers, and family members. Interviews were conducted in a variety of nursing facilities covering a broad geographic area of the state. Facilities were identified from a list generated on the Ohio Long-term Care Consumer Guide on the Ohio.gov website. All facilities visited listed Traumatic Brain Injury Care as a provided service.

Interview results indicated that most of the participants' TBIs were the result of motor vehicle crashes. Persons interviewed were predominantly male. The primary reason cited for nursing facility placements was the inability of family members to care for the person after the TBI. Many cited mental health or behavioral problems as the reason care cannot be provided in the community. Most of the persons interviewed had multiple mental health diagnoses, and many of them are on medications intended to address those issues.

With the exception of a few residents, the persons interviewed report not knowing about Home and Community Based Services (HCBS). Most nursing facility staff report that no efforts are made to discuss HCBS with the resident. Nursing facility staff report behavioral concerns or high level of assistance with daily living skills as the primary reason for not considering HCBS. Several individuals interviewed had minor nursing issues and were independent for daily living skills. They report behavioral challenges as the reason they cannot reside outside of the nursing facility. However, most persons interviewed want to leave their nursing facility and live in the community, either with family or with another caregiver. Most family members and nursing facility staff believe that many of the individuals interviewed could live in the community if the necessary supports were available.

Age Range	Gender	Primary cause of TBI	Primary cause of NF admission	Mental Health Diagnoses
23-78 years old	82% (31) male 18% (7) female	47% moving vehicle & pedestrian 21% falls 11% violence 11% suicide 3% blast 8% unknown	Family unable to continue care usually due to behaviors*	73.6%**

Table 1. Summary of data (* behaviors include aggression and self-injury; **common psychiatric diagnoses include depression, bipolar disorder, and psychosis.)

Persons interviewed

Interviews were conducted with 38 persons with a TBI diagnosis in their medical record. The ICD-10 CM listing of TBI diagnoses was used. These include:

S02.0, S02.1-	Fracture of skull
S02.8, S02.91	Fracture of other specified skull and facial bones; Unspecified fracture of skull
S04.02, S04.03-, S04.04-	Injury of optic chiasm; injury of optic tract and pathways; injury of visual cortex
S06-	Intracranial injury
S07.1	Crushing injury of skull
T74.4	Shaken infant syndrome

Interviews were conducted to understand the person with TBI from the perspective of the resident, family member, nurse or physician, and social worker. Interviews of family members and caregivers were conducted on site at the nursing facility or via telephone.

Interview protocol

The interview protocol focused on 3 content areas (see Appendix 3).

Content Area 1 asked questions to determine what needs the person has for a nursing level of care. These questions related to limitations in daily living skills such as self-care and mobility, the type of help the person would need to complete activities of daily living such as shopping and getting around in the community, and questions about level of supervision required to address safety concerns, medication administration, and behavioral or mental health issues.

Content Area 2 focused on the course of events that led to the person being in a nursing facility. This area focused on questions about how the TBI occurred, when the person entered a facility and length of stay, whether the person received rehabilitation before entering the nursing facility, and what led to nursing facility admission.

Content Area 3 sought information about the person's experience with HCBS. Questions were asked about whether the person had been referred for an assessment for HCBS, whether they had been found eligible, and if not, why.

Interview conditions

Interviews were conducted from October 2017 to January 2020. Prior to visits, a letter was sent to the nursing facility explaining the purpose of the visit. Scheduled visits were made to nursing facilities throughout Ohio. On the day of the visit, a meeting was held with nursing facility administration and staff to explain the purpose of the interview and to identify residents with a diagnoses of TBI based on the ICD-10 definition for TBI. With few exceptions, nursing facility staff were receptive and helpful during the interview process. Most nursing facility staff seemed unaware of the distinction between TBI and other diagnoses such as dementia or stroke. Generally, nursing facility directors of nursing or social workers were the staff members most familiar with TBI and residents diagnosed with it.

Residents were interviewed individually in various locations in the nursing facilities (patient rooms, common areas, conference rooms). If the resident gave permission, the resident's record was reviewed. All persons interviewed gave permission to review their records. If the resident gave permission to speak with others, nursing facility staff and family members were interviewed. All but two persons gave permission to speak with staff and family members. All interviews followed the pre-established protocol for each Content Area.

Interview results

Sixteen facilities were visited in 11 different counties (see Appendix 1). Thirty-eight individuals with TBI were interviewed. The age of individuals ranged from 23 to 78 years old, with 17 of the 38 under the age of 50 (see Appendix 2).

Common themes emerged from the interviews. The majority of residents identified with TBI in the facilities visited were male (31 males, 7 females). The most common cause of the TBI was motor vehicle crash. The second most common reason for the TBI was falls/jumps.

The most common reason for nursing facility placement was the inability of a family member to care for the individual after the TBI. Many of the residents went home after their acute treatment for TBI but increasing needs or aging/death of a caregiver resulted in their placement in the nursing facility.

Frequently, mental health issues or behavioral challenges were given as the reason for

nursing facility placement. This was the most common reason cited by caregivers as the barrier to community placement. Many of the persons with TBI also had several mental health diagnoses in their medical records. Frequent mental health diagnoses were schizoaffective disorder, major depressive disorder, anxiety, and bipolar disorder, with many residents diagnosed with multiple of these conditions. Almost all residents with mental health disorders are prescribed psychotropic medications. Only two individuals indicated, and charts confirmed, they were receiving specialized therapy for their TBI or mental health¹.

With only a few exceptions, persons interviewed did not know about HCBS and report that nursing facility staff or others did not discuss with them services that might be available for them live in the community. Many of the residents interviewed do not like living in the nursing facility and would like to return home to live with family or live alone in the community. Several residents did not have nursing needs that would require living in a nursing facility. In one case, family had chosen not to move a resident without nursing needs into the community due to poor decision-making regarding alcohol use.

Major Findings

The primary cause of TBI among persons interviewed was motor vehicle crash.

The second most common cause was falls/jumps. Most of the persons interviewed were male, and 17 of the 38 people interviewed were younger than 50 years old.

Most persons were admitted to the nursing facility because their family members could no longer care for them. The primary cause of placement was mental health or behavioral challenges that made it too difficult for the family member to keep the person at home.

Almost every person interviewed wanted to leave the nursing facility and live at home or elsewhere in the community.

A 43-year-old male was in a car crash and sustained a TBI at 10 months of age. He lived with his mother after the accident until his mother needed surgery and nursing facility placement for rehabilitation. He and his mother currently live in the same nursing facility. He is unhappy in the nursing facility because he does not have age-appropriate peers and he feels he does not get good care. He reports that his mother was his primary caregiver. He does not have complex medical needs and could live in the community but would need transportation, some help with activities of daily living and reminders for some tasks.

The majority of persons admitted to a nursing facility within two years of injury were over the age of 22.

¹ One person was receiving mental health counseling, and one person attended a specialized program for people with TBI available in the community.

Thirteen persons interviewed were admitted to a nursing facility within two years of their TBI. Ten of 13 persons admitted to the nursing facility were over the age of 22. Only 2 of those 10 were over the age of 60. The 3 admissions under age 22 were young people with catastrophic injuries who required maximum assistance to meet all basic needs. Most of these admissions were people in the age group least covered by HCBS waivers.

Behavioral challenges were cited as the main reason families and nursing facility staff were not considering placement in the community.

A 58-year-old male with a history of prior TBIs slipped and fell in his home. Since the last TBI, he has been living in a series of nursing facilities. He has a history of alcohol abuse and poor decision-making. He has no need for daily assistance and is independent in all activities of daily living. He has no nursing care need except the need to have reminders to take his medications. He would like to leave the nursing facility and live in the community. His guardian is opposed because of the poor decision-making behaviors. Per the nursing facility social worker, in order to live in the community, the person would need transportation, medication reminders, alcohol counseling, and some social work services.

Most of the persons interviewed have multiple mental health diagnoses and are prescribed multiple medications for the conditions. Yet, only two of the 38 people interviewed receive specialized services for TBI or non-pharmacologic treatment for mental health issues (e.g., counseling).

A 31 year-old female with children and a history of mental illness and homelessness was hit by a car when she walked into traffic during a suicide attempt at age 28. Prior to the attempt, her children were taken away at birth by child protective services due to homelessness. The resident would like to move out of the nursing facility and into the community with mental health supports and her guardian is in agreement. The resident is on a secured unit, and they have tried to step her down to a less secure unit with limited success. The resident only recently started counseling and is showing progress. This person would need continued mental health support to live in the community.

Caregivers and family members report that assistance with behavioral issues would be a necessary support for individuals to live in the community. Other necessary supports included assistance with activities of daily living and reminders for memory issues.

A 74-year-old male sustained a TBI from a fall at work at age 69. He returned home after the TBI but his wife could only care for him for 6 months and then he was admitted to a nursing facility. Both his wife and his nurses at the nursing facility think he could be supported at home with the right services. He is non-ambulatory and would need a lift. His wife reports that she cared for him at home for as long as she could until he developed behavioral challenges including being combative

during care and throwing himself on the floor. His wife visits him every day, and reports that she would love to have him home but would need supports, including a lift and care aides. Part of the reason she put him in the nursing facility is because she could not rely on aides showing up to help her when she had him at home. She currently pays someone to transport him home for visits a couple of times per year.

There is a lack of awareness among staff at the nursing facilities about TBI.

Most nursing facility direct care staff did not know the definition of TBI or how dementia or stroke were different from TBI. Many of the direct care staff were unable to identify residents with TBI. Generally, nursing facility social workers and directors of nursing were the staff most familiar with TBI and the residents with that diagnosis.

There were a handful of people interviewed whose needs were so high it would be difficult to support them in the community with the existing support system.

A 34-year-old male who was hit by a car while riding his bicycle has extensive medical and self-care needs and no family involvement. He has serious mental health issues, is non-ambulatory, and requires maximum assistance for all activities of daily living. Because of his high level of need, and lack of family to advocate for services in the community, he will likely remain in the nursing facility for long term care.

A 47-year-old female who was run over by a truck has significant mental health needs and related behaviors that are too much for her family to handle. The social worker at the nursing facility tried to get a waiver to move the resident into the community but was unable to find one with enough behavioral support.

A 35-year-old male who received a TBI from a blast injury requires maximum assistance for all activities of daily living and is non-ambulatory and non-verbal. He is unable to participate in any of his care at the nursing facility due to the significance of his injury.

Almost all persons interviewed did not know about the HCBS system and report they were not asked whether they would like to live in the community. Several persons had only minor healthcare needs and did not need nursing care.

Most nursing facilities did not talk with persons interviewed about the HCBS system. Most persons interviewed and their caregivers report that the idea of moving into the community with supports was never discussed with them after placement in the nursing facility. Only one person with TBI interviewed reported knowing about Ohio's waiver programs and the services available. Most caregivers and nursing facility staff did not know about waivers or understand the services available through waivers.

Conclusions

More work needs to be done to educate persons with TBI, their families,

caregivers, and nursing facility staff about options that are available to support community placement.

Almost all persons interviewed expressed dissatisfaction with living in a nursing facility and wanted to move home or into the community. Yet most persons interviewed, their family members, and nursing facility staff report that HCBS were never discussed as an option for moving into the community.

The existing HCBS system lacks services necessary to provide support in the community for people with TBI and behavioral health needs.

Nearly 75% of persons interviewed have multiple mental health diagnoses and are prescribed psychotropic medications. Nearly all of those persons have behaviors that are described by nursing facility staff and family members as preventing the person from living in the community. The one nursing facility social worker who tried to access waiver services for a resident discovered that the necessary behavioral supports were not available to support the resident in the community.

There may be an intervention point where the provision of appropriate behavioral supports in the family home could prevent nursing facility placement.

Most persons interviewed went home to live with family after their TBI. At some point, the family was no longer able to care for the person and they were placed in a nursing facility. Many family members report that they would bring the person home if supports in the home were available and reliable.

The prescription of multiple psychotropic drugs to individual with TBI in nursing facilities merits review.

The original interview protocol implemented for this project did not include a medication review. However, once the interviews began, it was apparent that many people with TBI in nursing facilities were prescribed multiple psychotropic medications for mental health diagnoses. At the same time, very few people interviewed were receiving other services, such as counseling or therapy, to address their mental health diagnoses. The apparent overreliance on medications as a response to mental health diagnoses and accompanying behaviors should be reviewed.

More attention should be given to the identification of persons with TBI in nursing facilities.

Nursing facilities house a large number of persons with TBI. The 2019 4th quarter MDS 3.0 Frequency Report indicates that 1,323 (1.93% of those with data) Ohio nursing facility residents had an active diagnosis of TBI during the previous 7 days. Nationwide, this number was 20,260 (1.60% of those with data). Ohio has approximately 960 nursing facilities, yet many of the facilities contacted through this project report having no residents with TBI. There appears to be a disconnect between the number of individuals that nursing facilities self-reported to DRO during the interview process

and the numbers reported in the MDS. This, and the lack of awareness about TBI among nursing facility staff, suggests that more attention needs to be directed to professional development on this topic.

About the Authors

Disability Rights Ohio is a non-profit corporation with a mission to advocate for the human, civil and legal rights of people with disabilities in Ohio. Since October 2012, Disability Rights Ohio has served as Ohio's Protection and Advocacy (P&A) system and Client Assistance Program (CAP). It is governed by a Board of Directors, primarily consisting of people with disabilities and family members of people with disabilities.

The Ohio Brain Injury Program at The Ohio State University exists to advance prevention and treatment that will improve the lives of Ohioans impacted by brain injury. The Brain Injury Program of Ohio recognizes brain injury as a major public health problem that contributes to preventable loss of life and disability. The Program seeks to assure that individuals with brain injury and their families have access to relevant information, quality healthcare and an effective system of services and supports.

Appendix 1

City/County where nursing facilities are located:

- Akron (Summit)
- Bellbrook (Greene)
- Celina (Mercer)
- Cincinnati (Hamilton) (2 facilities visited)
- City omitted due to size of town (Wayne)
- Coldwater (Mercer)
- Columbus (Franklin) (2 facilities visited)
- Hudson (Summit)
- Lima (Allen)
- Lucasville (Scioto)
- Newark (Licking)
- Springfield (Clark)
- Vandalia (Montgomery)
- Wooster (Wayne)