

Systems Analysis of Health and Community Services for Acquired Brain Injury in Ontario

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Report provided to the Ontario Neurotrauma Foundation by the Research Team:

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Executive Summary

1.0 Overall Purpose and Research Objectives

The overall purpose of the Systems Analysis of Health and Community Services for Acquired Brain Injury (ABI) in Ontario project was to describe the scope and nature of health and community services, the linkages that exist at the various points of the continuum, as well as linkages across the transitions from children to adult.

The following specific objectives were addressed:

1. To describe and analyze the **scope and nature of ABI services** across the continuum of services, across the lifespan of individuals living with ABI.
2. To describe the activity within services and the **flow of services across and between LHINs**, specifically as it relates to:

- Services being provided including capacity and description of services, including exclusion criteria
 - Distribution of services
 - Utilization of services, including access and waits for services
 - Coordination of services including linkages, partnerships, relationships and associations
 - Gaps in services
 - Urban/rural differences
3. To capture information on **wait lists** for services, whether services are provided by designated ABI programs or within generalized programs and the proportion of clients with ABI within generalized programs.
 4. To inform and enable the Ontario Neurotrauma Foundation (ONF) on a provincial level, in consultation with stakeholders to identify **frameworks** that might be helpful for Ontario to address ABI as a complex chronic disorder for adults, children, and youth.
 5. To describe **partnerships**, linkages, associations and relationships that exist for the delivery of ABI services.
 6. Identify opportunities where individuals could move to an alternate level of care (ALC) if an ALC in the community existed and what that would look like.
 7. To determine areas for **investment/recommendations** and **gaps in services**.

2.0 Methods

To achieve the overall purpose as well as the specific research objectives, a triangulation design was employed. This design is used when there is a need to validate or expand quantitative results with qualitative data, as is the case in the present study.

All organizations that receive Ministry of Health and Long-Term Care (MOHLTC) funding for ABI were targeted. Eight groups of stakeholders were identified including community-based organizations that belong to the Ontario Association of Community Based Boards for Acquired Brain Injury Services (OACBABIS), ABI community-based organizations funded through MOHLTC but not part of OACBABIS, community brain injury associations, community

care access centres (CCACs), rehabilitation hospitals, children's treatment centres (CTCs), acute care/trauma centres, and the local health integration networks (LHINs). Purposive sampling by LHIN was conducted for the community brain injury associations. In total, 94 organizations and representatives from the 14 LHINs were identified.

An environmental scan of the formal and grey literature was conducted to develop the relevant content areas of the survey, including potential frameworks and gaps in service, with consideration for the specific objectives of the current project. A draft of the interview guide was pilot tested with representatives from the Ontario Brain Injury (OBIA), a CCAC, a community-based organization, and a rehabilitation hospital. Based on the environmental scan and these consultations, seven separate interview guides/surveys were developed for the each of the identified stakeholders: community-based-OACBABIS, Community-based-non-OACBABIS, CCACs, community associations, rehabilitation hospitals (interview guides), CTCs, and acute care/trauma centres (electronic surveys). To address the proposed objectives of the study and in keeping with identified areas of study from similar reports from the grey literature, the selected topic areas included the following: - description of the program, - type of agency/organization, - populations served, - types of programs/services provided to clients with ABI, - eligibility/admission criteria for the program, - approach to service delivery, - staffing, - access to services, - wait for services, - capacity, - data/indicators tracked/available, - partnerships/ linkages/relationships, -future and successful initiatives, and - current issues/concerns and gaps. Approval from the Research Ethics Board at the Toronto Rehabilitation Institute was obtained.

Seventy-nine organizations/representatives were interviewed/surveyed. The following response rates were achieved by the stakeholder groups **targeted**: 100% for the OACBABIS community-based organizations (i.e., n=8/8); 64% for the non-OACBABIS community-based organizations (i.e., n=9/14); 67% for the CCACs (i.e., n=6/9); 83% for the community associations (i.e., n=10/12); 90% for the rehabilitation hospitals (i.e., n=9/10); 58% for the CTCs (i.e., n=11 of 19 of the 20 CTCs)¹; and 50% (i.e., n=12/24) for the acute care/trauma centres. Informed consent was obtained from all stakeholders. The majority of the key informant interviews were conducted by telephone. Results are representative of the percentage of responses received from each type of organization targeted.

Results derived from this project are limited by individual responses to the interviews/surveys. Although more accurate information may have been obtained if multiple people from one organization had been surveyed, the questions were pre-circulated to participants to encourage internal consultations and were reported by senior members from within the organization or program.

¹ For the purposes of this study, Holland Bloorview Kids Rehabilitation Hospital in Toronto (previously Bloorview Kids Rehab), which is both a children's treatment centre and a rehabilitation hospital, was surveyed as a rehabilitation hospital and as such, is not included in the data analyzed for Children's Treatment Centres.

3.0 Results

3.1 Scope of Services

- With the exception of CTC's, across all stakeholder groups and most of the LHINs (community-based organizations, community associations, including some rehabilitation hospitals) a small proportion of organizations served children (i.e., under the age of 16).
- A small proportion of organizations across LHINs provided counseling, behavioural support, psychological, and psychiatric services.
- A higher proportion of organizations reported exclusion criteria related to age, medical stability, degenerative conditions, and severe behavioural disorders.
- Consistent with findings on the changes in the case mix of the ABI population: a higher proportion of older adults with chronic co-morbid conditions and individuals with co-morbid mental illness were reported.

3.2 Access to Services

- A small proportion of organizations reported having mental health care professionals, including a general psychiatrist, neuropsychiatrist, clinical psychologist, and neuropsychologist.
- In the OACBABIS-community-based organizations, across the LHINs, there was a trade-off between clinical psychologists and neuropsychologists.

3.3 Wait List for Services

- Across all of the stakeholder groups, a high proportion of organizations maintained a waiting list.
- Across many of the organization types and across all the LHINs, the most dominant reasons for the wait list were not enough staff and not enough funding for services to meet demand.
- There was inconsistent/poor data on the waiting lists for *specific services within an organization*.

3.4 Data Indicators Tracked

- Most of the organizations reported an accountability agreement with the LHINs, and this was cited as the main reason for tracking indicators.
- There is a need for more organizations to track client outcomes, use benchmarks, and report indicators to outside organizations.
- In the OACBABIS-community-based organizations, the GTA LHINs tracked client outcomes, used benchmarks, and reported indicators to outside organizations.

3.5 Children's Treatment Centres

- 36% of organizations surveyed offered services for clients of up to 18 years of age.
- 64% provided education directly, as well as in collaboration with the school system.
- 36% offered psycho educational services.
- 8% offered services in neuropsychology.
- All offered counseling services, mostly through social (n=10) and psychological (n=1) services, as well as parental support/sibling/family support and education.

3.6 Acute/Trauma Centres

- Members of participating organizations identified the following as important solutions to facilitate discharge: inpatient rehabilitation and complex continuing care, slow stream rehabilitation, and behavioural support unit and community-based residential housing and support services.
- Only one organization reported having a protocol for ABI in the emergency department.

3.7 Alternate Level of Care

- Patients are not transitioned out of acute care ALC beds.
- Long wait lists for outpatient services (gap/unmet need) were reported for the following services: psychological/mental health, drug and alcohol, emotional, social and cognitive needs, job skills/vocational support, and rehabilitation.
- There are not enough suitable discharge destinations.
- No opportunities for ongoing service and support on discharge from acute and rehabilitation systems (services not available in individual's home region).

3.8 Acquired Brain Injury and Long-term Care

- Long-term care (LTC) is an inappropriate discharge destination for young people with ABI.
- More flexibility in the system needed (e.g., a few additional hours/week from CCAC services could enable an individual to stay in the community versus an inappropriate admission to a LTC).
- Individuals with ABI (of appropriate age) could be clustered and triaged to a particular LTC with ABI expertise, to avoid ALC (i.e., a discharge destination post-hospital).

4.0 Recommendations

4.1 Behavioural & Cognitive Challenges

- Enhance the capacity of successful programs around the province that enable engagement in meaningful activity.
- Develop expertise in the areas of behaviour and cognition, which are core to brain injury services.
- Support existing brain injury programs by the utilization of behaviour scientists through placement of students.

4.2 Addictions

- Treat ABI and substance use concurrently.
- Explore Substance Use and Brain Injury (SUBI) and other models being used across the province to determine the best fit for each community.

- Include children and youth in the programs to anticipate issues and engage in prevention.

4.3 Mental Health

- Enhance capacity through:
 - Building strong linkages across mental health and ABI systems with collaborative service, resulting in joint responsibility moving to a collaborative treatment/service model.
 - Break down barriers through cross training, information sharing, consultations, and utilization of OTN for consultations and training where possible.
 - Breaking down the silos between agencies, ministries, funding bodies, through joint projects, initiatives.
 - Increasing focus on the individual and the family/community well-being, requiring a paradigm shift.

4.4 Housing

- Need for more general affordable housing.
- Recognize flexibility is critical in developing innovative and effective housing options/programs for individuals with an ABI. *(see ALC recommendation)*

4.5 Children and Youth

- Need for more pediatric ABI inpatient beds and centres outside of the GTA.
- Replicate the Pediatric Acquired Brain Injury Community Outreach Program (PABICOP) as a model in various regions.
- There is a need for early identification, as well as consistent and shared records across schools, family physician offices, and other organizations/agencies
- Initiate transition services for youth at age 16, through CTCs, CCACs, and adult ABI service providers.

4.6 Emergency Department and Outpatient Services

- Need for consistent use of ABI protocols in emergency departments.
- Need for enhanced ambulatory rehab programs.

- Need for transportation supports to enable access to outpatient and community services.

4.7 Caregiver and Respite Services

- Create flexible models of respite and support to address needs of families and caregivers.
- Enhance capacity by collaborating and integrating with other population groups/initiatives wherever possible.

4.8 Lifelong Case Management

- Introduce System Navigators (community intervention coordinators) with access to teams (ACT type model) and expertise to provide community consultation, outreach, and support to staff and caregivers of individuals with ABI.
- For individuals with an ABI in LTC, need to support LTC facilities in developing expertise in ABI (i.e., enhanced capacity to provide appropriate services).
- For CCAC, need for increased flexibility in criteria, rules about eligibility, and numbers of hours of service.

4.9 Alternate Level of Care

- Individuals with ABI could be clustered and triaged to a particular LTC with ABI expertise to avoid ALC (i.e., a discharge destination post-hospital).
- Skills and training in generalist services dealing with ABI are needed (e.g., enhanced ABI services on acute care units to assist with behavioural issues, impulsivity control, safety risks, family support).
- Enhanced inpatient rehabilitation services (i.e., do not need *more* adult inpatient rehabilitation beds).
- More pediatric ABI inpatient beds and centres outside the GTA.
- Enhanced ambulatory rehabilitation programs;
- Need for (more) behaviour support programs.
- Housing and support for individuals with ABI (i.e., as a continuum of needs: variable hours service, outreach – from phone call/life line, in home support, 24 hour care),

and life-long case management (i.e., ongoing consultation service with access to teams (ACT-type model)).

- A particularly compelling solution/area of investment for the high number of ALC days in this population is the need for more community-based programs. This enables individuals to live at home in a familiar, comfortable environment, leading a greater likelihood of functionality and responsiveness to therapy. Active collaboration between hospitals and community-based services is needed to allow for this transition of care.