

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

Synopsis - Children and Youth Services

The Systems Analysis of Health and Community Services for ABI in Ontario was initiated 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 transitions from children to adult services. Specifically, the project team conducted a literature review, extensive *key informant interviews* with a sample of organizations from across the ABI continuum and across the province, including:

- ABI-specific and other community-based organizations (OACBABIS¹ and non-OACBABIS)
- community care access centres (CCACs)
- community brain injury associations
- rehabilitation hospitals

In addition, *on-line surveys* with acute care hospitals/trauma centres and children's treatment centres (CTCs) were conducted. A total of 79 interviews and surveys were conducted.

The project was designed to capture the majority of publicly-funded services, but was not an inventory of ABI services that are accessed by the population. It was limited to include only those general services where there was an identifiable critical mass or a cluster of services identified by stakeholders.

Research Team

Dr. Susan Jaglal – Principal Investigator
Professor, University of Toronto
Senior Research Scientist, Toronto Rehabilitation Institute

Rika Vander Laan, *Consultant*
Daria Parsons, *Consultant*
Charissa Levy, Executive Director, Toronto Acquired Brain Injury Network
Sarah Munce, Research Assistant

¹ Ontario Association of Community Based Boards for Acquired Brain Injury Services is a not for profit unincorporated association of not for profit charitable providers of rehabilitation services to persons living with the effects of an acquired brain injury residing in the province of Ontario.

Children and Youth

This synopsis provides highlights from the report in relation to health and community services for children and youth in the province. Following some key results and recommendations, implications are briefly discussed.

What the ABI Systems Analysis found

With the exception of Children's Treatment Centres, across all of the stakeholder groups in the province, there is a lack of services for children and adolescents with ABI.

- There is a lack of transitional programs for those adolescents 17 and 18
- All OACBABIS organizations provide services to adults, with only two of these organizations (in Hamilton Niagara Haldimand Brant and North West LHINs) providing services for children.
- Across LHINs, none of the non-OACBABIS community-based organizations provide services to children.
- One CCAC indicated that they did not serve children under the age of 16 and/or did not have a specific program for them
- Of the Community Brain Injury Associations surveyed, those in Central West, Mississauga Halton and North West LHINs provide services to children.
- Of the rehabilitation hospitals surveyed, only those in the Waterloo Wellington, Hamilton Niagara Haldimand Brant, and Toronto Central LHINs provide services for children.

Children's Treatment Centres² *(Survey responses were obtained by 11 of 19 of the 20 CTCs)*

- Almost three quarters (n=8; 73%) of the CTCs surveyed based their services on both physical and cognitive needs of the child, while the remaining CTCs (n=3; 27%) have services that are based primarily on physical needs.
- 7 CTCs (64%) provided education directly, as well as in collaboration with the school system and 36% offered psycho educational services
- 3 CTCs did not offer educational services
- All offered counseling service, mostly through social and psychological services, as well as parental support/sibling/family support and education
- 6 CTCs (55%) offered behavioural services, either directly or through consultation, while 45% (n=5) did not.

² For the purposes of this study, Holland Bloorview Kids Rehabilitation Hospital in Toronto, 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.

- Nine of the CTCs surveyed (82%) reported having a database to track children in their service. In the fiscal year 2001/10, 6 of the CTCs surveyed reported being able to provide data about children with an ABI, with 5 organization providing data. The range of the number of children in treatment was 6 to 300. Almost 90% of the CTCs reported having a wait list.
- Only two CTCs identified local or regional brain injury services as a partner.

Recommendations from respondents in regards to ABI services for Children and Youth

- There is a need for more pediatric ABI inpatient beds and centres outside of the GTA. This was provided as a solution for ALC.
- Replicate the Pediatric Acquired Brain Injury Community Outreach Program (PABICOP) as a model in various communities
- 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 collaborations with CTCs, CCACs, and adult ABI service providers

Implications for system planners and providers

The results of the study indicate that with the exception of Children's Treatment Centres, across all of the stakeholder groups in the province, there is a significant lack of services for children and adolescents with ABI. This may need to be revisited, as the Ontario ABI Dataset (Colantonio et al, 2009) found that over a four-year period the highest percentage of emergency visits for traumatic brain injury are among 0-30 year olds with the peak being among those 10-19 years of age.

One-third of the CTC's surveyed do not have educational services. Educational services are viewed as an important service to foster successful return to school for children who have sustained an ABI.

Only two CTCs identified local or regional brain injury services as a partner. This represents a gap in linkages and collaborations between organizations but can be seen as a valuable opportunity for the Ontario Association of Children's Rehabilitation Centres, the CTC's themselves, the Ontario Brain Injury Association and the Community Support Network (which includes the majority of the Community Brain Injury Associations and OBIA) to improve on this.

Forty-five percent of the CTC's surveyed did not offer behavioural services, either directly or through consultation. This likely has implications for individuals and families, as behavioural problems are common following ABI.

CTC service areas may not line up well with the LHINs. Some LHINs have a few CTC's within their region, others may have a CTC that serves a portion of the LHIN's geographic area. One LHIN does not have a CTC within its boundaries. It is not clear where children from these regions receive their services from in the absence of CTC services.