

T o r o n t o

**Acquired
Brain Injury**
N e t w o r k

**A Framework for the Future Planning of
Publicly Funded Acquired Brain Injury
Services in Toronto**

March 2006

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ACKNOWLEDGEMENTS

This initiative has been reflective of the spirit of integration and collaboration that exists among acquired brain injury ABI providers in Toronto and the Greater Toronto Area. The hard work, support and commitment of the Planning Committee are evident in the outcome. See Appendix A for a full list of Planning Committee members and further acknowledgements.

EXECUTIVE SUMMARY

Introduction

Background

Acquired brain injury¹ is a significant and growing health concern that requires a systemic and thoughtful planning response. The incidence and prevalence of acquired brain injury (ABI) in Toronto, as demonstrated by the epidemiological review contained in this report, illustrates the scope of the matter and the considerable impact that ABI has on the children and adults of the Greater Toronto Area and our healthcare system. Furthermore, the complexity and chronicity of brain injury, the diversity of its impact, and the lack of awareness that exists among healthcare providers, educators, employers and the general population compounds the challenges individuals and their families face and obfuscates the planning of healthcare.

In response to these concerns, the Toronto ABI Network² recognized the need for a more deliberate approach to service planning and set out to develop a framework that would allow for a proactive response to the anticipated system need rather than a continued reactive response.

In the spring of 2004, the Toronto ABI Network approached the Toronto Region of the Ministry of Health and Long-Term Care, highlighting the current need for services for those with an ABI in Toronto and area and advocating for a systems-level planning approach. To support these efforts, the Network also contacted the Toronto District Health Council (TDHC) to request its assistance with planning for long-term ABI services. From there a planning committee consisting of stakeholders from across the continuum was established (see Appendix A).

Objective

The objective of this initiative was to create a planning framework that would provide a consistent and deliberate process for planning for ABI services in order to develop recommendations for the delivery of ABI services in Toronto based on our understanding of the current and future need and capacity. The process of developing the planning framework illustrated the need and provided the starting point for the development of a coordinated provincial strategy for acquired brain injury services across the age continuum.

Data Review

The ABI Planning Committee, in consultation with the Toronto District Health Council's epidemiologists, conducted a data review consisting of pediatric and adult hospital and community service utilization data, incidence and prevalence rates of ABI and program costing. The process of collecting and interpreting data was made difficult by a number of issues inherent in the way that health information is currently gathered and reported in Ontario and illustrates how difficult it is to match supply and demand for ABI services.

However, the data review process did provide a basis for the committee to speculate about demand in relation to current service capacity and project future need. The challenges associated with the collection of brain injury data

¹ For the purpose of this initiative, the Toronto ABI Network definition of "acquired brain injury" was adopted: An acquired brain injury is damage to the brain which occurs after birth and is not related to: a congenital disorder, a developmental disability, or a process which progressively damages the brain (see Appendix B1). The damage may be caused: traumatically (i.e., from an external force such as a collision, fall, assault or sports injury), through a medical problem or through a disease process which causes damage to the brain (internal process or pathology) (see Appendix B2).

² The Toronto Acquired Brain Injury (ABI) Network is a consortium of 23 ABI service providers with representatives from across the health continuum. The Network was established in 1995 to address issues of fragmentation in the system and inequitable access to service for individuals with an acquired brain injury. Since its inception, the Toronto ABI Network has successfully worked towards enhancing access to and quality of acquired brain injury services across Toronto and has enhanced collaboration and communication amongst ABI providers.

are well recognized by the community and by the Ministry of Health and Long-Term Care. A project to develop a database for tracking brain injury incidence in Ontario is currently underway, through funding made possible by the Ontario Neurotrauma Foundation. As a result, this report does not make specific recommendations regarding the need for better data collection but the committee strongly supports the initiative already underway and recognizes that its success will be invaluable in the future planning for ABI services. Once the improved mechanisms for data collection are realized, the healthcare community will be better equipped to answer questions related to what services are required and in what quantity and distribution.

Current State of ABI Services in Toronto

The current publicly funded system of ABI services in Toronto is made up of a combination of acute care, acute rehabilitation (hospital-based and community-based) and longer-term services (clinical case management, day programming and supportive housing) aimed at supporting community reintegration across the age continuum. Each piece of this system is essential in addressing the various needs of individuals with an ABI at particular stages in their recovery. In general this 'system' is set up such that individuals with an ABI move through in a linear fashion (i.e., acute care ⇒ inpatient rehabilitation ⇒ home/outpatient rehabilitation ⇒ community based rehabilitation ⇒ community support). However, not everyone requires each component of service and not everyone moves through the continuum in the same way.

Service Capacity and Identified Gaps

In this context, the ABI Planning Committee identified a number of factors and trends that are impeding their ability to provide services to people with ABI in Toronto at various points across this continuum, including:

- The transition from acute care to rehabilitation and the tension caused as a result of acute care facilities feeling pressure to discharge patients earlier and the rehabilitation hospitals wanting to admit people at the point in time when they are most ready to participate in rehabilitation.
- The insufficient capacity of community support available to people demonstrated by extensive wait lists (including supportive housing, support to reintegrate into school, work and community, opportunities for productive meaningful activity, community therapies and case management). It is the experience of ABI service providers in Toronto that this area represents the most significant gap (in terms of capacity relative to demand) in the service delivery of the ABI system, and has a ripple effect on the rest of the system.
- The challenge in providing appropriate support for those with severe behavioural issues.
- The challenge in working with partner providers to facilitate an understanding about ABI and a coordination of services (e.g., working with educators to support children and youth as they return to school).
- The challenge in accessing appropriate services and support for those with a dual diagnosis of ABI and Mental Health and/or ABI and substance abuse/misuse.
- The difficulty in identifying and treating mild brain injury as it often goes undiagnosed or misdiagnosed.

Transitions/Coordination

Given that ABI is both an acute and a chronic health issue, the Planning Committee identified issues of access that occur at different points in an individual's recovery and spans their lifetime. These issues are associated with transitions from one program or service to another and sometimes from one system to another (e.g., the move from pediatric services to adult services involves different ministries as well as different organizations). Another issue related to transitions and the need for coordination is one that we can only speculate about at this point. As the Local Health Integration Networks (LHINs) in Ontario take on their mandate to plan, coordinate, integrate, manage and fund care services, consideration will need to be given to how individuals move across one LHIN to another as may be required to access necessary services. This is a particularly critical issue for Toronto as services in Toronto will be spread across five LHINs. It is also a unique concern for those individuals with

ABI. Given the complexity of ABI and the often intense services required, it will not be possible or appropriate to provide all required ABI services in each LHIN. Therefore, it is expected that coordination and sharing of resources will be required.

Family/Caregiver Support

“Most individuals with brain injury will spend the longest period of their lives living in the community”³ and it is often the families who are required to provide and maintain lifelong support for the individual with the brain injury, yet it is felt that this is the most conspicuous area where the system falls short. In planning for a system that is responsive and emphasizes crisis prevention, consideration needs to be given to the role of the family and how we can support families to maintain the valuable role they play in the ongoing care needs of individuals.

Funding

The Planning Committee strongly advocates for sufficient funding to meet the needs of the ABI population in Toronto, however it also recognizes the need to examine the manner in which funding is allocated to determine if there are efficiencies that could be realized by redirecting resources in addition to increasing resources.

Human Resources

As with other areas of healthcare, those providing services for individuals with ABI struggle to create and maintain an appropriate pool of human resources. A systematic response to these issues is needed to plan appropriately for services at this time and into the future.

Planning Framework

These factors and system issues provide the rationale for the creation and consistent implementation of a planning framework to develop an ABI strategy across the age continuum. The activities of the committee are reflected in the planning framework but its primary purpose is to provide a mechanism to monitor and plan for a system of ABI services on an ongoing basis. The components of the framework are outlined in Section 4 of this report and are embedded in the recommendations that follow.

Recommendations for the Future of ABI Services in Toronto

Through the process of conducting this epidemiological and system review, the committee identified a number of recommendations that reflect the importance of the guiding principles and provide a starting point for bridging the gap between the identified demand for services and Toronto’s current capacity to respond.

1. That planning for ABI services in Toronto take on a population-based approach.

‘Population based principles provide the scientific basis for action and the rationale for the formation of a defensible policy.’⁴ Population based planning incorporates a clinical epidemiological perspective, evidence based practice, an emphasis on outcome and an emphasis on prevention:⁵ each will need to be incorporated into the development of an ABI strategy such as outlined below in recommendation #3.

³ Boschen, K., et. al. (2005) “Identification of Best Practices in Reducing Stress and Burden for Family Caregivers of Persons with an Acquired Brain Injury”. Unpublished.

⁴ Ibrahim, Michel A. et al (2001). “Population-Based Health Principles in Medical and Public Health Practice” *Journal of Public Health Management Practice*, 7 (3), 75-81

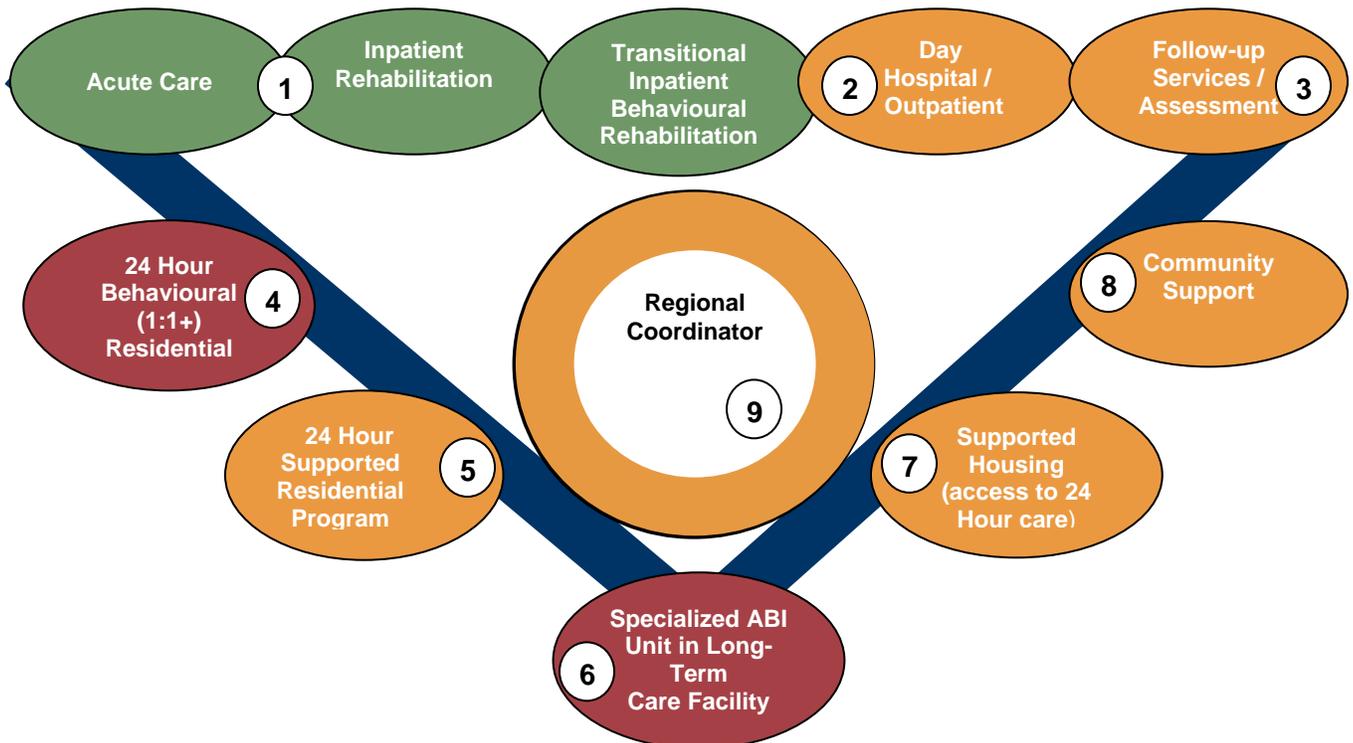
⁵ Ibrahim, Michel A. et al (2001). “Population-Based Health Principles in Medical and Public Health Practice” *Journal of Public Health Management Practice*, 7 (3), 75-81

To undertake population based planning, the following activities are required (some of which are already in progress):

- Systematically collect incidence and prevalence data.
- Establish protocols for diagnosing and identifying those with brain injury (particularly mild brain injury).
- Establish a process to monitor needs from family/client perspectives through community consultation.
- Identify appropriate outcome indicators to predict resource requirements following brain injury.
- Monitor utilization of healthcare and community services and collect and analyze wait list information to ensure that available service and support delivery models are appropriate to meet need. This may include the systematic evaluation of service delivery in areas that are identified as not currently meeting needs to develop appropriate recommendations such as increased funding, changes to admission/discharge criteria, changes to average length of stay, etc.

2. That services be developed to fill the gaps that currently exist in Toronto as depicted in the model below and that funding be appropriate and sufficient to sustain each component of the service.

Model of Current and Proposed ABI Services in Toronto



Specific recommendations related to this model are embedded in the table in Section 5.2 of this report.

3. For the community of providers in Toronto and in Ontario to engage in the development of a comprehensive ABI strategy, similar to those that have been developed for other health populations.

The planning framework presented in this document provides part a starting point, in terms of the monitoring required to understand supply and demand and the mechanisms to plan accordingly.

However, to ensure an integrated model of services that is responsive, appropriate and sustainable over the long term, it is considered necessary to bring together key players to establish a comprehensive strategy to guide planners and providers in the future delivery of ABI services.

1.0 INTRODUCTION

1.1 Background

Acquired brain injury (ABI) is a significant and growing health concern that requires a systemic and thoughtful planning response. Brain injury is a comparatively new health issue as medical advances continue to make it possible for more and more severely injured individuals to survive. Service providers and funders need to find ways to respond accordingly.

The incidence and prevalence of ABI in Toronto, as demonstrated by the epidemiological review contained in this report, illustrate the scope of the matter and the considerable impact ABI has on the children and adults of the Greater Toronto Area and on our healthcare system. Furthermore, the complexity and chronicity of brain injury, the diversity of its impact and the lack of awareness that exists among healthcare providers, educators, employers and the general population compounds the challenges individuals and their families face and obfuscates the planning of healthcare.

Developing a framework for service delivery is essential to ensure an appropriate response to the evolving needs of the ABI population. The process of planning services is complicated by the fact that people with an ABI have a normal life expectancy, often with significant disability. The needs of individuals with an ABI can remain constant and can span a lifetime and, therefore, for planning for ABI needs to incorporate the same type of prevention, health and promotion and management focus as other chronic disease populations.

As the incidence of ABI persists over successive years, the prevalence of those requiring support grows and hence, so does the demand on services. In the past, the Ministry of Health and Long-Term Care has responded to the recognized demand by providing priority funding for specialized ABI services. Additionally, in the early 1990s, the Ministry developed the infrastructure for a significant increase in community-supported independent living and long-term residential programs. Much of this was developed in order to repatriate Ontarians with ABI who were being treated in the United States⁶ and was administered in the absence of a policy framework for ABI services.

The availability of these services has not kept up with the growing demand and we, as service providers, often find ourselves in a situation of responding to crises. Although there are excellent examples of specialized ABI programs in Toronto, capacity remains a significant concern as the waiting lists for these programs can be many years long, making access to services insurmountable.

In response to these concerns, the Toronto ABI Network recognized the need for a more deliberate approach to service planning and set out to develop a framework that would allow for a proactive response to anticipated system need rather than a continued reactive response.

In the spring of 2004, the Toronto ABI Network approached the Toronto Region of the Ministry of Health and Long-Term Care, highlighting the current need for services for those with an ABI in Toronto and vicinity and advocating for a systems-level planning approach. To support these efforts, the Network also contacted the Toronto District Health Council (TDHC) to request its assistance with planning for long-term ABI services. The TDHC took on this task in partnership with the Toronto ABI Network and its established Planning Committee (see Appendix A), providing the project team with the expertise of the TDHC's planners and epidemiologists. Upon closure of the TDHC in March 2005, the Toronto ABI Network continued the project with the support of a contracted consultant. The final document was completed by the Toronto ABI Network secretariat in consultation with the Planning Committee.

⁶ Carolyn Sherk Consultants, "A Continuum of Opportunity for People in Ontario with Acquired Brain Injury", *Carolyn Sherk Consultants, Prepared for the Continuum of Opportunity Task Force*, December 1994

In 1994, the Ministry of Health and Long-Term Care commissioned a similar planning report, *Continuum of Opportunity for People in Ontario with Acquired Brain Injury*.⁷ It is the intention of this current initiative to build on the work previously completed by the Continuum of Opportunity Task Group, to highlight the remaining recommendations and to bring in a Toronto-specific perspective. Although some of the recommendations from the provincial report have been implemented, many have not and remain relevant today. Of particular concern are the recommendations concerning population-based planning and providing the resources to ensure ABI services meet the current and future needs of the population.

1.2 Objective

The objective of this initiative was to create a planning framework that would provide a consistent and deliberate process for planning for future ABI services and to develop recommendations for the delivery of ABI services in Toronto, based on our understanding of the current need and capacity. The process of developing the planning framework illustrated the need and provided the starting point for the development of a coordinated strategy for ABI services across the age continuum.

This report highlights the gaps in current ABI services and formulates recommendations, based on these gaps and incidence and prevalence projections, to serve this population now and into the future.

To accomplish this, the Planning Committee met regularly for six months and undertook the following activities, the results of which form the content of this report:

- Gathered and reviewed incidence and prevalence data to understand the current and projected future demands on service.
- Conducted a scan of the current landscape of ABI services through a survey of providers in order to understand the current supply and identify gaps.
- Conducted key informant interviews to contribute to the above landscape scan and to identify common issues and service needs.
- Conducted a literature review to investigate best practices regarding service delivery models.
- Developed a framework for the future planning of ABI services.
- Developed recommendations for the provision and planning of current and future ABI services in Toronto, including a proposed service model.

1.3 Definition of Acquired Brain Injury

For the purpose of this initiative, the Toronto ABI Network definition of ‘acquired brain injury’ was adopted.

An acquired brain injury is damage to the brain which occurs after birth and is not related to:

- a congenital disorder;
- a developmental disability; or
- a process which progressively damages the brain. (See Appendix B1)

The damage may be caused:

- traumatically (i.e., from an external force such as a collision, fall, assault or sports injury); or
- through a medical problem or disease process which causes damage to the brain (internal process or pathology). (See Appendix B2)

An ABI can result in physical, cognitive, emotional and/or behavioural disabilities in varying degrees, depending on the location, nature and severity of the injury. Generally, the extent of the impairment can be linked to the severity of the injury. That is, those with moderate-to-severe injuries tend to demonstrate a severe and complex

⁷ Carolyn Sherk Consultants, “A Continuum of Opportunity for People in Ontario with Acquired Brain Injury”, *Carolyn Sherk Consultants, Prepared for the Continuum of Opportunity Task Force*, December 1994

range of deficits and generally require more intensive (and often life-long) supports. Similarly, those with mild brain injury often make a good recovery and can return to many, if not all, aspects of their pre-injury life. However, it is important to recognize that there is a significant group of individuals who experience a mild brain injury who continue to have deficits that can be considered severe and they can struggle with long-lasting and debilitating impairments. This group is not well supported, largely because the deficits are not recognized initially or are not attributed to the ABI.

Throughout this report, 'ABI' will be used as a reference to both traumatic and non-traumatic brain injuries, 'TBI' will be used to denote sections where there was only evidence for traumatic brain injuries and 'NTBI' will denote sections where there was only evidence for non-traumatic brain injuries.

1.4 Project Scope, Assumptions, Limitations

As one of its initial tasks, the Planning Committee established a project charter that defined the scope of the project. (See Appendix C)

As this project originated in Toronto, the scope was limited to services solely in Toronto (defined by the old municipal boundaries of Toronto, Scarborough, Etobicoke, East York, York and North York). It is recognized that people outside of Toronto access services within the city, given the concentration of specialized acute care and rehabilitation services. Therefore the investigations of the project focused on the location of the service provider and not the home address of the patient.

This project was challenged by incidence, prevalence and utilization data that was not readily accessible, or in some cases nonexistent, which are outlined in detail in the next section of this report.

2.0 DATA REVIEW

With assistance from the Toronto District Health Council's epidemiologists, the Planning Committee conducted a data review consisting of pediatric and adult hospital and community service utilization data, incidence and prevalence rates of ABI and program costing. The sources of data include:

- Ontario Brain Injury Association
- British Columbia Ministry of Health Guidelines for Planning Brain Injury Services and Support (2002)
- Statistics Canada (1986-1987) Health Activity Limitation Survey
- Inpatient Discharge Abstract Database, MOHLTC Provincial Health Planning Database (2004)
- Ministry of Health and Long-Term Care, Finance & Information Management Branch (2005)
- Toronto Acquired Brain Injury Network Database

The process of collecting and interpreting data was complicated by a number of issues inherent in the way that health information is currently gathered and reported in Ontario. Most studies to date have focused on TBI information as it tends to be easier to collect. Even still, available TBI data is usually limited to hospital admissions and does not include emergency department or clinic visits or deaths prior to reaching the hospitals. Further, given its complexity and the diversity of associated symptoms, brain injury often goes undiagnosed or misdiagnosed, especially in the early stages of recovery. When a TBI is one of multiple injuries suffered by the patient (many that are life threatening and more easily identifiable), the presence of a brain injury may not be of primary concern and therefore may not be adequately recorded.

Gathering and understanding the data for mild brain injury is of particular concern, as individuals often do not seek medical attention for some time (or if they do go to the emergency department they are sent home without appropriate follow-up) and by the time they seek medical attention again, the connection between the current complaints and the injury sustained to the head may be lost.

The collection and interpretation of data was also challenged by difficulties in obtaining NTBI data during the service utilization survey. Conducting such a survey on a hospital-wide basis was impractical given the committee's time and resources as it would have required involving other teams and other departments of the hospitals which were not represented on the committee and for whom ABI was only a small part of their caseload. Therefore, it was decided that the survey would be limited to the trauma departments, understanding that valuable data related to NTBI would be missed.

The challenges associated with the collection of brain injury data are well recognized by the community and by the Ministry of Health and Long-Term Care. As a result, a project to develop a database for tracking brain injury incidence in Ontario has been funded by the Ontario Neurotrauma Foundation and is currently generating interest at the MOHLTC. Therefore, the authors of this report have not made specific recommendations regarding the need for better data collection but the committee strongly supports the initiative already underway and recognizes that its success will be invaluable in the future planning for ABI services. Once the improved mechanisms for data collection are realized, the healthcare community will be better equipped to answer questions related to what services are required and in what quantity. The data review process did provide a basis for the committee to speculate about demand in relation to current service capacity and project future need.

As a first step in the data review for this planning framework project, the committee engaged in considerable discussion to reach consensus on a list of ICD-9 codes for which data would be extracted (see Appendix D). These codes were chosen based on the understanding that their inclusion would ensure a comprehensive representation of the incidence of ABI. Since the system was changed from ICD-9 to ICD-10 during the extraction period, the epidemiologists converted the ICD-9 codes to ICD-10 (see Appendix D). Once the extraction was complete, the committee reviewed the data in detail to determine if the results were consistent with their experience and understanding of the system, or whether the codes needed to be modified to more accurately capture the ABI population. Further extractions were completed as was necessary.

2.1 Incidence/Prevalence of Acquired Brain Injury

2.1.1 Incidence

Incidence refers to the number of new cases of ABI in a given year. Although incidence and prevalence data for ABI is not well captured in Canada, a comprehensive review of available national and international data was recently published in “*An Analysis and Dissemination of Current Neurotrauma Incidence and Causal Data in Ontario*,” released by the Ontario Neurotrauma Foundation. The report provides data about admissions to Ontario hospitals, international incidence rates, prevalence and outcome measurement data. Details from this report will not be repeated here.

For this initiative, the Planning Committee focused on two sources that have estimated the rates of TBI and applied their findings to Toronto’s population:

- 1) The Ontario Brain Injury Association (OBIA) has estimated rates of TBI to be approximately 1.57 per 1,000 for the total population and 1.7 per 1,000 for children 0-18 years. These are based on a US study and are adjusted for the Canadian population.⁸
- 2) A study done in British Columbia (BC) in 2002 estimated ABI rates to range between 1.95 to 3.5 cases per 1,000, with traumatic rates at 1.1 to 2.0 per 1,000, mid range of 1.5 per 1,000.⁹

In applying these rates to Toronto, it was found:

- Using the BC formula, 5,090 to 9,140 new cases of ABI were estimated among Toronto residents in the year 2003 (mid range 7,120). These projections are based on the incidence rates and population data available to the TDHC at the time of the data review.
- Of these 7,120 cases, approximately 55% (3,920) were caused by trauma. The majority of the traumatic cases 80% (5,696) were mild, 10% (712) were moderate and 10% (712) were severe.
- These figures match relatively well with estimates obtained using OBIA rates which predict that the total number of new cases of TBI in 2003 were 4,107, of which 3,324 sought medical attention. Of these 3,324 people, 80.0% were mild ABI cases, 9.0% were moderate, and 6.0% were severe. According to the OBIA estimates (rate of 1.7 per 1,000 children, 0-18 years), approximately 750 children sustained an ABI in 2003 and 615 (82%) sought medical attention. Of the 82% who sought medical care; 529 (86%) were mild cases, 49 (8%) were moderate cases and 37 (6%) were severe cases.

2.1.2 Prevalence

Prevalence refers to the total number of persons living with an ABI at a given point in time. Many people with ABI require prolonged and sometimes life-long support. Hence, it is important to understand prevalence information to be able to assess system needs and plan for long-term supports and services.

The prevalence rates captured in this report were obtained from the following sources:

- 1) A literature review done by the Ontario Ministry of Health and Long-Term Care, 1994. The estimates of the prevalence of ABI among the population ranged from 150 to 439 cases per 100,000 of the population, with the majority of estimates closer to 150 per 100,000.¹⁰
- 2) The 1986-87 Health Activity Limitation Survey (HALS) by Statistics Canada. The survey indicated that 156 people per 100,000 aged 14 years and over were disabled and had memory or thinking problems as a result of

⁸ Ontario Brain Injury Association <http://www.obia.on.ca>

⁹ British Columbia Ministry of Health’s “Guidelines for Planning Brain Injury Services and Supports”, 2002

¹⁰ Ontario Ministry of Health and Long-Term Care, 1994

an “injury to the brain.” Sixteen percent of these persons were living in institutions. The rate from HALS is close to the lower limit of the range of the Ministry of Health review.

These sources are several years old and were unfortunately the most up-to-date sources available. The committee was comfortable using this data as a starting point as it was our belief that the environment has not changed in a substantial enough way to invalidate the assumptions that could be drawn from this data.

These two sources, applied to Toronto population data, provide the following information:

- Based on the prevalence rates evident in the 1994 Ministry review and applying them to 2003 population rates, there were between 3,917 and 11,465 people diagnosed with an ABI in Toronto. Such a wide range in numbers makes effective planning for services challenging and consideration will need to be given to how we can better estimate those with an ABI who will require rehabilitation and ongoing support (e.g., outcome measures that can form the basis of a predictive model).
- The HALS rates, applied to 2003 population data, suggest there were approximately 3,374 people in Toronto 14 years and over who had a physical disability and also had problems remembering or thinking as a result of an injury to the brain. Of these people, 540 (16%) were living in institutions, while the remaining 2,834 likely required follow-up and/or rehabilitation services and needed day-to-day support and care, vocational services, specialized housing and other forms of community support (although the report did not specify the level of service required for this group).

2.1.3 Projected Incidence

According to the projections using the BC study rates, the total number of new cases of ABI (traumatic and non-traumatic) among Toronto residents will increase from 5,090 to 9,140 in 2003 and from 5,456 to 9,794 in 2012. The increase based on the mid range is 7,117 to 7,625 (an increase of 508 patients).

According to the projections based on the OBIA rates, the number of Toronto residents with an ABI will increase from 4,100 in 2003 to 4,393 in 2012 (an increase of 293 patients). Children aged 0-14 living with ABI will increase by 22 (from 763 to 785).

Although these numbers may seem small, the impact of ABI is such that even a relatively small increase in prevalence can place significant demands on the system

2.1.4 Projected Prevalence

According to the projections resulting from the Ministry review, the total number of people living with ABI (traumatic and non-traumatic) in Toronto will increase from 3,917 to 11,465 in 2003 and from 4,197 to 12,284 in 2012. This is an increase of between 280 to 819 people.

Projections based on HALS rates are closer to the lower estimate of the Ministry rates. Based on this rate, the number of Toronto residents 15 years and over living with ABI will increase from 3,374 in 2003 to 3,642 in 2012 (an increase of 268).

Table 1 : Projected Incidence & Prevalence of ABI for Toronto Residents, 2005, 2008, 2012

	Rate/ per 1,000 population	ABI Estimate for 2003	ABI Projections for 2005	ABI Projections for 2008	ABI Projections for 2012	% Growth between 2003 and 2012
Incidence						
BC study-total ABI (lower range)	1.95	5,093	5,195	5,320	5,456	7.1 %
BC study-total ABI (upper range)	3.5	9,141	9,331	9,557	9,794	7.1 %
BC study-total ABI (mid range)		7,117	7,265	7,441	7,625	
OBIA TBI rate (total population)	1.57	4,100	4,185	4,287	4,393	7.1 %
OBIA TBI rate (children 0-14) ¹¹	1.7	763	829	824	785	2.9 %
Prevalence						
Ministry review (1994) (lower range)	1.50	3,917	3,996	4,093	4,197	7.1 %
Ministry review (1994) (upper range)	4.39	11,465	11,695	11,978	12,275	7.1 %
HALS	156	3,374	3,395	3,500	3,642	7.9 %

The numbers related to prevalence and projected prevalence raised questions and concerns for the Planning Committee. The Ontario Neurotrauma Foundation's *An Analysis and Dissemination of Current Neurotrauma Incidence and Causal Data in Ontario* reports the prevalence of Americans living with the effects of a brain injury to be a little more than 2% of the population. Our prevalence data suggests somewhere between 0.15% of the population to 0.439%. Although direct comparisons cannot be made because the ONF report is using US data, the degree of the variation was surprising.

To understand the data and provide some context, the committee looked at what was expected (given a number of assumptions outlined below) and what is reported elsewhere. As an exercise to test the data the projected prevalence was considered against a number of key assumptions and calculated to 2012. It is important to note that this exercise does not provide alternative numbers as it is based on assumptions and hypothetical numbers. However, it does raise some questions that indicate the need for further study.

Key assumptions (based on the breakdown of the numbers from the OBIA and BC data):

- 80% of the total number have mild injuries.
- 10% of mild injuries need care in Year 2.*
- 10% of the total number have moderate injury.
- 62% of moderate injuries need care in Year 2.*
- 10% of the total number have serious injury.
- 35% of serious injuries need care in Year 2.*
- Increase in incidence will be 7% by 2012.
- 90% survival rate.

* Note: A significant limitation in these assumptions is that it is unknown how many of the 62% of individuals with moderate injuries and needing rehab in Year 2 continue to need support in subsequent years.

¹¹ The increased incidence in children in 2005 and 2008 is reflective of Toronto population projections for these years.

Expected Projections of Prevalence										
	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
New cases	3324	3350	3376	3402	3429	3455	3482	3509	3537	3564
Still need support from previous years	0	575	1096	1570	2001	2394	2752	3079	3378	3651
Total that need support	3324	3925	4472	4972	5430	5849	6234	6588	6914	7215

These numbers cannot be used to definitively predict service need as they are hypothetical projections; however, they do highlight the issue of growing prevalence of ABI based on a steady annual incidence and on the chronicity of ABI. Therefore, these numbers, in conjunction with the prevalence rates reported in Table 1, point to the need for system planners to be cognizant of the expected growing demand on already limited resources available to those with ABI.

The challenges faced by the committee as it gathered and interpreted the data further emphasize the need for a systematic method of collecting reliable data. As already indicated, the ABI Database being developed through ONF will contribute significantly to the availability of accurate data, which is the underpinning of effective system planning.

2.2 Utilization of Healthcare Services

2.2.1 Utilization by Diagnosis

Accidental falls and motor vehicle crashes (MVC) are the most common causes of TBI and accounted for approximately three-quarters of all separations¹² in 2001/2002.¹³ This data is also corroborated by the survey conducted by the TDHC of the ABI providers. The survey results show that all respondents indicated the majority of their current clients (as of March 2005) were seeking services as a result of a MVC.

The three most common ICD-9 diagnoses associated with NTBI in Toronto in 2001/2002 were ‘other coma’ (e.g., hypoglycemia, anoxia) (34%), followed by secondary malignant neoplasm of brain (14%) and intracerebral hemorrhage (12%).¹⁴

2.2.2 Hospital Utilization

Data from hospitalization due to ABI was obtained from the Inpatient Discharge Abstract Database (DAD) contained in the Ministry of Health and Long-Term Care Provincial Health Planning Database. Table 2 and Table 3 in Appendix E highlight the separations (hospital discharges), LOS, ALOS and Alternate Level of Care (ALC) utilization by age group for those with ABI in an acute care setting.¹⁵ This data illustrates that NTBI and TBI account for 9,387 separations (or discharges) from Toronto acute care hospitals. The largest cohort by age for NTBI is 45-64 years, while the distribution of TBI is more evenly shared across age groups with a slight majority occurring for the 25-44 age group. Table 3 (Appendix E) indicates that the majority of hospital separations due to TBI are for people aged 25-44 years, followed by those over 75 years. This can provide the beginnings of a demographic profile of those sustaining brain injuries and which types of services are most needed. That is, different services and supports are required to respond to those over 75 years (who may need support to remain in home or will require placement), compared with those between the ages of 25-44 who may need more support related to vocational re-entry.

¹² *Separations* refers to discharges from hospitals; they do not reflect individual patients.

¹³ Canadian Institute for Health Information. Canadian Institute for Health Information data, 1998. CIHI, Provincial Health Planning Database. Toronto: 2000.

¹⁴ Ibid

¹⁵ Ibid

This source also indicates that NTBI patients have extended stays in hospital. In 2001/2002, there were a total of 94,717 days leading to an average length of stay (ALOS) of 31.1 days.¹⁶ This is longer than the ALOS for total acute separations which ranges from 5.6 to 6.0 days.¹⁷ It is expected that the longer ALOS can be attributed to the severity of their condition and the complexity of ABI.

Traumatic ABI patients also had considerable stays in ALC beds. ALC beds are for patients who are considered non-acute treatment patients and are waiting for placement in chronic care units, homes for the aged, nursing homes, rehabilitation facilities or other extended care institutions or home care programs. In 2001/2002, there were 5,837 ALC days for traumatic ABI patients.¹⁸ Further, a GTA Rehab Network report showed that ABI was one of the most prevalent rehab groups of patients awaiting rehabilitation in ALC across the five snapshots administered.¹⁹ This serves to illustrate the complexity of ABI, the challenges the system has in appropriately treating and transitioning those with complex ABI and the need for the system to find alternative responses to ensure that people are able to get to the level of care they need when they need it.

Table 4 in Appendix E illustrates that the majority (91.6%) of TBI separations occur in the emergency room of the hospital, i.e., they are not admitted to an acute care unit. This confirms the belief that many individuals may not be followed medically after a brain injury and that there may not be appropriate mechanisms in place to assess and treat the difficulties associated with brain injury that are not immediately apparent. Educating emergency department doctors and family doctors about the impact of brain injury is extremely important given this information. It illustrates the need for the development of a protocol for identifying ABI to assist physicians in diagnosing, treating and referring those with patients who are not linked into specialized services from the outset.

As seen in Table 5 (Appendix E), the majority of NTBI separations from acute care hospitals in Toronto are discharged; Table 6 indicates that majority of these people are discharged home. This data, along with the knowledge that people are accessing community services many years post diagnosis,²⁰ highlights the fact that the prevalence data may be understating the number of people who are living with the effects of an ABI.

2.2.2 Rehabilitation Utilization

Through the Toronto ABI Network's tracking of the ABI rehabilitation referrals, we know that people with ABI are discharged from an acute care setting to rehabilitation. This data provides information about the demand for rehabilitation by those with ABI. Tables 7 and 8 (in Appendix E) illustrates that 576 and 697 referrals were received in 2003 and 2004 respectively.

¹⁶ Canadian Institute for Health Information. Canadian Institute for Health Information data, 1998. CIHI, Provincial Health Planning Database. Toronto: 2000.

¹⁷ Toronto District Health Council (2002), "Toronto Local Health System Monitoring Report"

¹⁸ Canadian Institute for Health Information. Canadian Institute for Health Information data, 1998. CIHI, Provincial Health Planning Database. Toronto: 2000.

¹⁹ GTA Rehab Network (2004) "Analysis of Alternate Level Of Care (ALC) Snapshots: Patients Awaiting Rehabilitation in ALC and Inpatient Rehabilitation Capacity" www.gtarehabnetwork.ca

²⁰ Toronto ABI Network Database, <http://www.abinetwork.ca/home.htm>

It is important to note that the Toronto ABI Network receives very few pediatric referrals as they generally go directly from SickKids and other acute facilities to Bloorview Kids Rehab. In addition, these numbers only reflect the referrals that are received by the Toronto ABI Network, they do not reflect incidence of ABI. This information can provide a general sense of the demand on inpatient resources because the majority of inpatient referrals are managed by the Toronto ABI Network. This cannot be said for the community services as these programs accept referrals from many sources.

To further illustrate inpatient ABI utilization, Tables 9 and 10 demonstrate the separations from the ABI program at Toronto Rehabilitation Institute (Toronto Rehab), the largest inpatient ABI program in Toronto.

Year	Number of Separations
1998/1999	128
1999/2000	151
2000/2001	154
2001/2002	187
2002/2003	187
2003/2004	210

Year	Number of Separations
1998/1999	43
1999/2000	54
2000/2001	68
2001/2002	129
2002/2003	105
2003/2004	122

This data was provided by Toronto Rehab (from a recent Toronto Rehab report to the Ministry of Health and Long-Term Care) to demonstrate the steady increase in the number of separations from inpatient rehabilitation and an increase in the number of outpatient separations. Further examination is required to determine what role changing LOS may have played in the increasing number of separations.

2.2.3 Community Care Access Centre Utilization

Data was obtained from the Ministry of Health and Long-Term Care and is based on aggregations of ICD-9 codes for traumatic and non-traumatic ABI identified by the committee. The findings from the CCAC²¹ were as follows:

- The number of admissions due to ABI in Toronto CCACs increased from 437 in 1995/1996 to 534 in 2000/2001 and then decreased to 413 in 2002/2003 (the impact of SARS needs to be considered when interpreting this data).
- Admissions vary by age group and type of ABI. In 2002/2003, seniors 65 years and over accounted for the nearly half of the admissions (51%) followed by adults 45-64 years old (29%). The proportion of seniors is higher among the non-traumatic than traumatic admissions (51% vs. 43%).
- In 2003, there were a total of 470 active home care clients with ABI diagnoses. Fifty-three percent (251) of these had non-traumatic diagnoses while 47% (219) had traumatic diagnoses.
- The total number of units of ABI services provided by Toronto CCACs decreased from 23,798 in 2000/2001 to 16,872 in 2002/2003 (a 29% decrease). In the same period, the number of clients served decreased by 47% (from 480 to 255). Average units/clients served have increased from 49.6 to 66.2 (a 34% increase). This data seems to indicate that the clients being served have greater needs than previously, thus using more resources. This corroborates the notion that people are living with more acute and complex symptoms. It should also be noted that the CCAC ABI Program recently changed its eligibility criteria to include only those living with an ABI for 5 years or less. This change was made in response to the increasing demand and the inability of the CCAC to respond to that increased demand, considering its static resources.
- In 2002/2003, homemaking/personal support/attendant/respite-CCAC outreach accounted for the largest number of units provided to ABI clients, followed by occupational therapy. However, case management

²¹ Collected directly from CCACs and the MOHLTC Finance and Information Management Branch, 2005

accounted for the largest number of clients (39%) and expenditure (34%). In 2001/2002, the average units per client varied from 1.4 (case management) to 304.9 (homemaking/personal support/attendant/respite-CCAC outreach).

- Funding information for home care service use by ABI clients in Toronto was only available for the year 2002/2003. In 2002/2003, the total expenditure for specialized ABI services was \$1,028,250.
- Table 11 (below) reports the ABI admissions to Toronto CCACs for 2003/2003. This data illustrates that CCAC serves approximately twice the number of individuals with an NTBI as compared to a TBI. This is likely due to the availability of insurance funding and private services for those involved in a motor vehicle crash (a large portion of the TBI cohort).

Age group	Non-Traumatic		Traumatic		Both	
	#	%	#	%	#	%
0 - 18	6	2.2	7	5.0	13	3.1
19 - 24	<5	0.4	9	6.4	10	2.4
25 - 44	42	15.4	28	20.0	70	16.9
45 - 64	85	31.1	35	25.0	120	29.1
65 - 74	64	23.4	22	15.7	86	20.8
75+	75	27.5	39	27.9	114	27.6
Total All Ages	273	100.0	140	100.0	413	100.0

Source: MOHLTC Finance & Information Management Branch

2.2.4 Community Support Services

This service area arguably constitutes the greatest need and is the least understood; therefore the committee would have liked to focus much more attention on available data sources. Unfortunately there was little data for the committee to review. Section 3 of this report provides a description of what constitutes community support services.

In 2002/2003, there were a total of 19,102 units²² of services provided by the community support services sector to 54 clients. These services amounted to a total expenditure of \$4,653,794 for the Ministry of Health and Long-Term Care. For outreach services, there was a total of 21,862 units²³ provided to 299 clients which amounted to a total expenditure of \$1,654,183.²⁴ The cost associated with this service is high considering the relatively low number of clients being supported because it reflects the more severely injured who have high levels of ongoing resource requirements.

Evidence from the provider survey and statistical analysis of the community support service agencies' databases show that:

- More clients are being admitted than are discharged in a particular year. This may illustrate that while there are increasing pressures on programs to admit new individuals, existing clients cannot be discharged because of the chronicity of their impairment (i.e., the support needs do not diminish).
- There are more males receiving services than females.
- The majority of clients are in the range of 25-64 years of age. It is important to note that this is to some degree reflective of the eligibility criteria of these programs.

²² Unit for residential service constitutes a 24 hour day

²³ Unit for outreach service varies depending on the service (1 hour for community 1:1 support and ½-day for day program)

²⁴ Ontario Ministry of Health and Long-Term Care (2002), "Making It Happen: Summary Report of Community Mental Health Services and Supports"

http://www.health.gov.on.ca/english/providers/pub/mhitf/central_east_pen/summary_report.pdf

Both psychiatric and alcohol/drug problems are an issue for many ABI clients. For example at Community Head Injury Resource Services of Toronto (CHIRS), 40% of the clients have mental health problems while 21% have alcohol/drug abuse problems. This illustrates a need for partnering and resource sharing among providers in the ABI, mental health and substance use sectors.

2.3 System Costs for Treating Acquired Brain Injury

There is no Canadian data available regarding the specific economic impact of brain injury. However, SMARTRISK reported that the economic burden of all unintentional injuries²⁵ in Canada in 1995 was \$8.7 billion and in 1996 the economic burden to Ontario alone was \$2.9 billion.²⁶ Data from the US illustrates that attendant treatment costs associated with TBI cost more than \$37 billion annually.²⁷

Comparative studies looking at cost differentials for various treatment and service options were very difficult to find in Canada so the committee looked to international studies to provide a starting point for this part of the review. A randomized control study in the United Kingdom measured the cost of providing outreach rehabilitation in the home versus in an institutional setting. The results indicated that outreach per capita cost was about £6,000 as compared to £100,000 for institutional medical costs.²⁸ Another US study, where a patient receiving regular phone calls from a nurse to assist with rehabilitation was compared with institutional rehabilitation, indicated that the physical outcomes were the same while the costs were estimated at \$51,840 per patient for hospital rehabilitation and \$504 per patient in the home.²⁹

These studies only demonstrate the results for two specifically-defined treatment options and only provide two examples. However the considerable variance in the economic impact of the treatment options points to a need for planners to look at this issue very closely and dedicate some resources to investigating the true costs of service delivery.

²⁵ This only reflects the costs associated with TBI, not NTBI.

²⁶ Walker, Janice, et.al., (2002) An Analysis and Dissemination of Current Neurotrauma Incidence and Causal Data in Ontario (Ontario Neurotrauma Foundation Report) <http://www.onf.org>

²⁷ Martin, E., et.al. (2003), "Telephonic Nursing in Traumatic Brain Injury: A study shows the effect of psychiatric nurses", *American Journal of Nursing*, 103 (10)

²⁸ Powell, J. et.al. (2002), "Community based rehabilitation after severe traumatic brain injury: a randomised controlled trial", *Journal of Neurological and Neurosurgical Psychiatry*, 72: 193-202

²⁹ Salazar, A., et.al. (2000), "Cognitive Rehabilitation for Traumatic Brain Injury: A Randomized Trial", *Journal of the American Medical Association*, 283(23) 3075-3081

3.0 CURRENT STATE OF ACQUIRED BRAIN INJURY SERVICES IN TORONTO

Toronto is unique to other areas of the province as demonstrated below,³⁰ and as such demands a unique response in relation to health service planning:

- Toronto is the largest urban area in Canada. Its population is approximately 2.6 million with a wide variety of socio-demographic and cultural backgrounds.³¹
- Toronto's population expands to 3.5 million in the daytime.
- Toronto's population changes at a rate that is significantly higher than the rest of the province due to the effects of both immigration and refugee settlement.
- Toronto's population is growing and is reflective of the changing trends seen worldwide that are leading to greater pressures on the health system. That is, the population is characterized by increasing income disparities, changing demographics (e.g., aging population), changing consumer expectations and advances in healthcare technologies that can create a new more complex patient profile.
- A recent TDHC review of hospital separations in 2001/2002 revealed that one-third of admissions to Toronto's community hospitals and one-half of admissions to teaching hospitals originated from outside Toronto.³²

Toronto has developed a wide range of specialized ABI services and is often incorrectly considered resource-rich in comparison to other districts. However, on a per capita basis Toronto remains under-resourced and issues of capacity continue to present a significant challenge to the provision of ABI services.

Specialized services in Toronto for those with an ABI essentially began in 1978 when the first transitional group home in North America for adults with ABI was developed. Ashby House was then a small program that over the years became the multi-service ABI agency known as CHIRS. Additional community based resources were also available through what is now known as COTA Health. In 1987 funding was provided to Hugh MacMillan Centre (now known as Bloorview Kids Rehab) to provide ABI rehabilitation services for children. Since that time specialized and priority programs have been enhanced and created in a number of hospitals and community organizations (including Toronto Rehab, Bridgepoint Health, West Park Healthcare Centre, COTA Health, and Toronto CCAC, ABI Program).

The current publicly funded system of ABI services in Toronto is made up of a combination of acute care, acute rehabilitation (hospital based and community based) and longer-term services aimed at supporting community reintegration. Each piece of this system is essential in addressing the various needs of individuals with an ABI at particular stages in their recovery. In general this 'system' is set up linearly (i.e., acute care ⇒ inpatient rehabilitation ⇒ home/outpatient rehabilitation ⇒ community based rehabilitation ⇒ community support). However, not everyone requires each component of service and not everyone moves through the continuum in the same way. Through the ABI/MS Rehab Pilot Project (September 2002), the Toronto ABI Network and the GTA Rehab Network found that those who were able to move through the continuum in the linear way (as it is designed) generally had a more positive rehabilitation experience while those who needed to access services differently (e.g., at a different time post injury or outside the typical pathway) experienced more challenges in accessing what they needed.

Furthermore, the system of healthcare delivery for ABI is unique, given the interaction of the public sector with the private sector for those with third party funding (e.g., automobile insurance or WSIB). This intersection provides benefits as some individuals are able to access timely resources through their private benefits. It is also challenged

³⁰ Toronto District Health Council (2004), "Toronto Health System Framework", *Toronto District Health Council*.

³¹ Toronto District Health Council (2004), "Toronto Small Health Planning Areas: A Population-Based Approach To Constructing New Health Planning Areas in the City", *Toronto District Health Council*.

³² Toronto District Health Council (2004), "Toronto Small Health Planning Areas: A Population-Based Approach To Constructing New Health Planning Areas in the City", *Toronto District Health Council*.

by a complicated system involving public and private providers, lawyers and insurers, all with different and not always well-defined roles.

Against this context, the Planning Committee identified a number of factors and trends that are contributing to or impeding their ability to provide services to people with ABI in Toronto.

3.1 Service Capacity and Identified Gaps

A survey conducted by the Planning Committee of the participating members' ABI programs revealed a picture of the capacity for ABI clients in existing Toronto programs. The hospital-based programs reported waiting lists that ranged from two weeks to six months, depending on demand at the time and type of program requested (i.e., the wait for Slow-to-Recover Rehabilitation tends to be longer). The community programs reported waiting lists ranging from a few weeks to many years, again depending on the service requested with residential programs reporting the longest waiting lists, sometimes in excess of 10 years. All of the programs cited capacity (defined as too few spaces) as the major reason for the wait.

Acute Care ⇒ Rehabilitation

As a large metropolitan city and a regional provider of trauma care, Toronto provides ABI services to residents from outside the city in its major acute care and teaching hospitals. To illustrate, a review of the Toronto ABI Network's central referral system demonstrated that between 36% and 38% of referrals received from 2003-2005 were for patients with home addresses outside of Toronto.³³ These patients often were discharged to the Toronto-based rehabilitation centres, primarily due to the availability of specialized ABI rehabilitation programs in Toronto, and therefore this population needs to be accounted for when considering the capacity requirements for ABI rehabilitation.

Through managing the referral system, the Toronto ABI Network and its members have identified an apparent trend in shorter LOS in acute care. This is in response to increased pressure on acute care facilities to reduce beds and reduce lengths of stay and the growing number of individuals who are being discharged home to wait for inpatient rehabilitation. This has raised concerns as a number of individuals are refusing to come back into hospital for rehabilitation once they have spent some time at home. As a result, some individuals are not receiving the level of rehabilitation they require because they do not recognize the full impact of their impairment until much later, at which point attempts to access appropriate therapies are complicated by the length of time since injury.

Concurrently, there appears to be increasing pressure on rehabilitation facilities to take patients earlier. There is a growing concern that people are coming into rehab before they are fully ready to benefit. Given the limits to the amount of time available to people for an inpatient rehabilitation stay, some worry that this is not the best use of resources. This issue needs to be fully explored in order for service providers and planners to be confident that the right people are getting the right service at the right time. Once a complete review has been conducted a strategic response can be developed, structuring the system in such a way that the pressures on acute care can be acknowledged while at the same time ensuring that people are being admitted appropriately into rehab at the time when they are best able to benefit. For example, 'stepdown' or 'transitional' units, which allow people to remain in hospital until they are ready for rehabilitation or until a bed becomes available, could be part of the solution to this issue. Recently, short-term convalescent beds within LTC facilities were funded by the Ministry of Health and Long-Term Care to provide a similar resource to a different population. It is expected that this will not be a viable option for many ABI patients waiting for rehabilitation given the very complex nature of their impairments, including significant cognitive and physical deficits, agitation and behavioural issues. However, the notion of

³³ GTA Rehab Network and Toronto ABI Network, (2002), "Results of the ABI/MS Pilot Project"
<http://www.abinetwork.ca/downloads/abims-report-20020930.pdf>

convalescent beds does have a place in a system of ABI services, albeit in a different environment with different resources.

Community Based Support

Currently the system of community based ABI programs in Toronto provides services ranging from structured and supported residential options for adults to case management and community or outreach support. It is the experience of ABI service providers in Toronto that this area represents the most significant gap in the ABI system of service delivery (in terms of capacity relative to demand) and that this gap has a ripple effect on the rest of the system. Insufficient services or inadequate support at the community end of the continuum can result in a deterioration of client functioning, sometimes including drug and alcohol abuse and forensic involvement; and unmanageable strain on families; hence a reliance on other, usually more intense and/or inappropriate, resources. Conversely, adequate community support is associated with enhanced quality of life in the community, which in turn has been demonstrated to result in reduced use of other resources (such as hospitals).³⁴

- *Supported Housing:*

Specialized publicly funded ABI supported housing programs exist in Toronto, primarily through three organizations (i.e., CHIRS, McLeod House and ABI Possibilities Inc.). The level of support provided by these organizations varies depending on the mandate, structure and staffing of the program. For example, McLeod House and ABI Possibilities support individuals who require regular assistance with activities of daily living and may require access to support twenty-four-hours-a-day but can be unsupervised for periods of time during the day. ABI Possibilities does provide personal care as required and is providing support to one individual who needs direct 24-hour support. CHIRS provides a variety of residential services, some which are similar to that described above, as well as more highly structured programs for individuals with significant cognitive and physical impairment who need a high level of 1:1 support for many activities and must be supervised constantly.

The most significant system issues associated with supportive housing for those with an ABI relate to capacity and flexibility on the part of the organization to respond to changes in their environments. As indicated, the waiting list for appropriately supported living for high need individuals is many years long. This puts an incredible burden on the individual, their families who are left to provide whatever support they can with whatever resources they have available, and the system which struggles with supporting people in inappropriate settings (e.g., hospitals, psychiatric departments, LTC facilities and homeless shelters).

While capacity certainly is a significant issue, a contributing factor is the current limitations within the system for organizations to exercise flexibility in service provision. Enhancing the system through the creation of alternate models of community-based service will result in freeing up resources in other areas as well as ensuring that individuals are able to move towards more appropriate levels of service. For example, it is reported that individuals are unable to move to residential options with reduced resources despite demonstrated readiness, simply because there is no capacity at that lower level of service. It can be even more challenging to move them to a more highly resourced program if the support they are receiving no longer meets their needs.

- *Productive/Meaningful Daily Activity:*

Empirical studies and our experience indicate that individuals in the community benefit from opportunities to engage in productive meaningful activity through vocational, avocational and social activities (Warden et al

³⁴ Bigelow, Douglas A., Young, Deborah, J. (1991). Effectiveness of a Case Management Program *Community Mental Health Journal*, Vol. 27, No.2

2000 and Salazar et al 2000). This offers the dual benefit of supporting the individual in maintaining their functioning and social/emotional well being as well as providing respite opportunities for families on a regular basis. While these resources are available to some individuals, there is a need for significant enhancement within our current system.

- *Community-based Therapy/Case Management:*

Following the traditional course of acute rehabilitation (i.e., through inpatient and day hospital programs) individuals can usually access ongoing therapy in the home through the Community Care Access Centres (CCACs). In Toronto, Halton, Peel and York Regions, CCACs have specialized ABI services recognizing that individuals with the complex sequelae of ABI often require intervention from therapists who have experience with and understanding of ABI.

This program provides a valuable resource to individuals and is generally able to respond quickly; however, issues arise related to the ability of the CCAC ABI program to remain involved over time, despite the chronicity of ABI and reoccurring need for therapy at different points of transition.

Case management is recognized as an effective model for maintaining individuals in the community. Currently in Toronto individuals with an ABI can access case management through the CCAC while they are receiving active services, and also through COTA Health. In addition, case management-type services are often a component of the services provided by community-based programs such as McLeod House, ABI Possibilities and CHIRS.

The effectiveness of case management is empirically established in the mental health system. It has been demonstrated that those who receive Assertive Community Treatment (ACT) experience reductions in psychiatric hospitalization and a higher level of housing stability (Phillips et al, 2001). It is important to note, however, that what is provided through ACT teams is different from more traditional case management. Specifically, it is more than simply the coordination of services; but rather includes direct service provision. In addition, it incorporates flexibility in the intensity, timing and duration of the service that is not available through what we currently understand as ABI case management.

Examples of studies to illustrate the effectiveness of community support services and case management could also be found in the ABI literature. As a case in point, a study by Pace et al of the home and community-based neurorehabilitation (HCN) model whereby rehabilitation is provided wherever the individual will ultimately live and work concluded that “mobile rehabilitation teams can provide effective treatment in the natural environment as measured by individualized goal achievement and family and funder satisfaction.”³⁵

Additionally, a study by Feeney et al was designed to test the hypothesis that individuals with behavioural challenges following brain injury can benefit from community supports as well as be served in a more cost-efficient manner outside of an institution. The results show that not only did these people live successfully in the community 3-4 years post treatment, but also the cost saving for the system was estimated at \$1.7 million per year (USD) for only 80 individuals.³⁶

Further, a study conducted by DePompei et al highlights the benefits of using case management when treating people with ABI. This study specifically states that there is a need for case managers to assist after TBI with information and referral services or to prepare the family or person to advocate in the community. It also

³⁵ Pace, et.al (1999), “Characteristics and outcomes of a home and community-based neurorehabilitation programme”, *Brain Injury*, 13(7).

³⁶ Feeney, et.al. (2001), “Community Supports for Individuals with Challenging Behavior after Brain Injury: An Analysis of the New York State Behavioral Resource Project”, *Journal of Head Trauma Rehabilitation*, 16(1).

states³⁷ that services must span across a wide continuum of care, from intensive to long-term care, and recommends the following actions be taken in order to achieve this:

- Promote an interagency planning process for individuals, families and service providers to problem solve and organize existing services to meet the needs of people with TBI.
- One member accepts responsibility for follow-up with individual or family.
- Provide training to individuals and service providers.

Rehabilitation/Services for those with Behavioural Issues

The committee members and key informants have highlighted an access issue regarding a lack of resources for those children and adults with significant behavioural challenges, an issue which appears to affect each part of the continuum of healthcare services. While behavioural difficulties are often part and parcel of the sequelae of ABI, there are clear limitations to the degree of behaviour that can be managed within many of the existing programs/services. Individuals with very significant behaviours are often unable to access inpatient programs as rehabilitation hospitals often do not have staffing models that allow for the level of supervision or support required. In addition, finding long-term living options for these individuals is very challenging and often results in people living in inappropriate settings (e.g., acute care or complex continuing care).

The West Park Healthcare Centre's ABI Behaviour Services program does provide Toronto with a behavioural rehabilitation option for some adults. This program provides transitional rehabilitation that focuses on stabilizing behavioural issues that can arise following a brain injury. This program is not designed to address the individual's long-term support needs, as many require highly structured programs on discharge, which are not sufficiently available in Toronto. In addition to these individuals being unable to move to a more appropriate environment once they have completed West Park's program, this gap in the system also makes it difficult to access West Park's ABI Behaviour Services program itself as the program's five beds are often blocked for many months past the targeted LOS. It is felt that if this program was able to function as it was designed (that is, as a short-term treatment program), the number of beds would be sufficient to support Toronto. However, sufficient resources need to be developed to support the transition from West Park's ABI Behavioural Service to the community. Such programs, which effectively provide long-term residential options for those with very severe behavioural issues, have been developed in other regions of Ontario but currently do not exist in Toronto.

Rehabilitation/Services for those with Dual Diagnosis of ABI/Mental Health

As a further complicating factor to accessing appropriate services, many children and adults with brain injury either have a pre-existing mental health diagnosis or develop psychiatric issues following the brain injury and therefore require services that can address both their mental health issues as well as those associated with their ABI. It is the experience of this group that such individuals have difficulty accessing either stream of services as each side abdicates responsibility to the other, failing to agree over which issue is preeminent (the ABI or the mental health diagnosis).

Although the Neuropsychiatric Unit at Whitby Mental Health Centre provides a program with a specialized ABI/mental health service, it has a strict catchment area that leaves more than half of the city under serviced. The Centre for Addiction and Mental Health (CAMH) recently shifted the focus of its neuropsychiatric program, redirecting its energies to geriatric psychiatry to the exclusion of those with ABI. This recent change contributes to the ABI population having very little access to mental health services, despite their disproportionate need for such support. While there has been some success in negotiating service plans between individual ABI and mental health providers, there needs to be greater collaboration across programs to meet the complex needs of this dual diagnosis population.

³⁷ DePompei, R., et.al. (2001), "Traumatic Brain Injury Collaborative Planning Group: A Protocol for Community Intervention", *Journal of Head Trauma Rehabilitation*, June

Recognizing that there are few psychiatrists in Toronto who have expertise in ABI (and many who do have waiting lists that exceed 12 months), the Toronto ABI Network recently investigated the issue to determine potential solutions. Through this investigation it was established that there are a number of psychiatrists in Toronto who, although they do not currently have a significant case load of individuals with ABI, would be interested in receiving education regarding the needs of those with an ABI, ostensibly to enhance their ability to support this population. This is an issue that requires a systematic and strategic response that can include a short-term plan to provide education to those psychiatrists who are interested in this population but also needs a more comprehensive long-term plan that includes educating those studying psychiatry about ABI and attracting young doctors to the field.

Services for Mild Brain Injury

The term ‘mild’ brain injury can be misleading as the consequences of such an injury are often quite severe. A National Institute of Health Consensus Development Panel (NIH) has concluded that mild brain injury is significantly under-diagnosed and early intervention is often overlooked.³⁸ Delays in identification and inadequate treatment of mild brain injury can lead to physical, functional, cognitive and behavioural challenges. Not only does the injury have a long-term social impact on the individual, but the family is also affected.³⁹ In Toronto there are two multidisciplinary brain injury clinics: Sunnybrook & Women’s College Health Sciences Centre TBI Clinic and St. Michael’s Hospital Head Injury Clinic. These clinics identify people most in need of follow-up services, ensure patients receive appropriate information, complete medical assessments, access and coordinate services, and collaborate with other providers across the system to best meet patients’ needs. However, they can only be accessed if someone has identified that there is a brain injury and the physician involved is aware of the resources available. The Sunnybrook & Women’s College TBI Clinic sees patients with TBI up to three months post-injury and will follow-up with them for up to one year. The St. Michael’s Hospital Head Injury Clinic sees patients with TBI from their own emergency department and trauma unit and takes referrals from community partners (GP offices from across Ontario). Because of the increased demand, the waiting time for an appointment is currently five months, which is a long time to wait for a diagnosis and treatment, particularly in situations where people are unable to return to work or daily activities.

3.2 Transitions/Coordination

Given that ABI is both an acute and a chronic health concern, the Planning Committee identified issues to access that occur at different points in an individual’s recovery and spans their lifetime. These issues are associated with transitions from one program or service to another and sometimes from one system to another. Following a brain injury, individuals tend to move through a course of recovery and rehabilitation that is (in general) set up linearly, although not everyone requires each component and not everyone moves through the system in the same way. The distinct components that make up this course are provided by different teams and, often, different organizations. To illustrate, an individual can move from acute care in one organization to inpatient rehabilitation at a different organization and community rehabilitation at a third organization, requiring at least three separate transitions at the earliest stages of recovery.

These points of transition are further complicated for some individuals if they need to move from one system of services to another. The provision of healthcare services for children is quite distinct and separate from that of adults. This is reflected not only in the manner and location through which services are provided but also the sources through which they are funded. The transition from one system to the other can be challenging and yet it is an inevitable course for many children who sustain brain injuries and requires not only the transition from one organization to another but also collaboration across the various ministries involved (i.e., Ministry of Children

³⁸ NIH Consensus Development Panel: Rehabilitation of Persons with Traumatic Brain Injury (1999)., JAMA 282 (10), 974-983.

³⁹ Fearnside, M. & Simson, D. (1997) Epidemiology in Head Injury. Chapman & Hall, London.

and Youth Services, Ministry of Education, Ministry of Health and Long-Term Care and the Ministry of Community and Family Services).

Challenges in transitioning from one sector of service delivery to another are also faced by those at the other end of the life span as adults with an ABI age and need to begin accessing seniors' services. This requires that LTC facilities, among other providers, be prepared to manage the unique needs of those with an ABI. It also requires that we, as providers of ABI services, understand the issues that will face those with living with an ABI as they age. As ABI is relatively a new health concern, the study of this issue is in its infancy and requires dedicated consideration.

Another issue related to transitions and the need for coordination is only speculative at this point. As the LHINs in Ontario take on their mandate to plan, coordinate, integrate, manage and fund care services, consideration will need to be given to how individuals transition across one LHIN to the other as may be required to access necessary services. This is a particularly critical issue for Toronto as services in Toronto will be spread across five LHINs. It is also a unique concern for those with ABI. Given the complexity of ABI and the intensity of services often required, it will not be possible or appropriate to provide all required ABI services in each LHIN, therefore it is expected that coordination and sharing of resources will be required across LHINs.

Toronto has already established key mechanisms for ensuring smooth transitions from one service to another through the Toronto ABI Network's management of a central referral system for adults. This system has been working well, particularly in relation to the transition from acute care to the next phase of rehabilitation. It becomes much more difficult to facilitate referrals out into the community given the complexity of the system, the scarcity of some components of service and the limited resources available to the Network. When the needed services are not available, significant resources are required to case manage and advocate in order to develop appropriate plans. Currently Toronto does not have the means to provide intensive case management for the region. Additional case management resources will be required, perhaps linked to each Toronto LHIN, if we are to ensure that people are able to navigate the system of services and gain access to the services required at the time required.

3.3 Family/Caregiver Support

"Most individuals with brain injury will spend the longest period of their lives living in the community"⁴⁰ and it is often the families who are required to provide and maintain lifelong support for the individual with the brain injury yet it is felt that this is the most conspicuous place where the system falls short.

Many families see it as their responsibility and their wish to care for their family member at home and do not want the individual to be institutionalized, however our current system does not provide for this option. Due to the current way services are structured and funded, families often do not get access to the support they need to maintain their family member at home, even in cases where it is the most cost-effective and humane option. In spite of the lack of available support, many families choose this route and as a result "sacrifice careers, ambitions, relationships and personal leisure to care for an injured family member."⁴¹ Under these circumstances, families can burn out. The level of care cannot be sustained and in some cases, individuals and families find themselves in crisis situations without sufficient support.

A recent study led by Dr. Kathryn Boschen investigated family caregivers and issues associated with stress and caregiver burden. This study put forward a recommendation for a model of services that would be "available to family caregivers across the continuum: acute, inpatient, and long-term community living."⁴²

40 Boschen, K., et. al. (2005) "Identification of Best Practices in Reducing Stress and Burden for Family Caregivers of Persons with an Acquired Brain Injury". Unpublished.

⁴¹ Ibid

⁴² Ibid

In planning for a system that is responsive and emphasizes crisis prevention, consideration needs to be given to the role of the family and how we can support them to maintain the valuable role they play in the ongoing care needs of individuals. A model of services should incorporate more options for families to receive the support required to keep the family member at home when this is the desired option and, when it is a feasible and efficient, use of resources.

3.4 Funding

The Planning Committee made a conscious decision not to focus on the issue of adequacy of funding for ABI services. It is well and clearly established that Toronto has capacity issues in relation to ABI services and the logical assumption is that some of this is rooted in funding shortfalls. We are also aware that there are limits to the availability of financial resources for Ontario's healthcare system. Therefore, while the Planning Committee advocates strongly for sufficient funding to meet the needs of the ABI population in Toronto, it also recognizes the need to examine the manner in which funding is allocated to determine if there are efficiencies that could be realized by redirecting resources in addition to increasing resources.

Recently, funding for ABI services in the community has been tied to individuals, often in response to crisis situations. This approach precludes appropriate and anticipatory planning and it creates a scenario where individuals in crisis are given access to services while others in need but not in crisis have to wait many months and even years for services.

Furthermore, key stakeholders advise that the current manner of funding for ABI services often does not allow for flexibility. Increased flexibility would give service providers the opportunity to develop a support model that can adjust to meet the changing needs of their clients in a responsive manner. This flexibility is a much-needed component if we want individuals to be able to move through the system to the most appropriate level of support. For example, individuals in highly resourced 24-hour residential programs sometimes progress to the point of requiring reduced services; however they are unable to move within the system because organizations do not have the freedom to modify service delivery.

3.5 Human Resources

As with other areas of healthcare, those providing services for individuals with ABI struggle with creating and maintaining an appropriate pool of human resources. The specific education and training in relation to ABI for most healthcare professionals is limited, therefore, the system relies on individuals to independently develop an interest and establish expertise in treating and supporting those with ABI.

For some professions, it is difficult to recruit people to specialize in ABI given the complexity of the system and the population. As already discussed, the Toronto ABI Network recently conducted a survey of all psychiatrists in Toronto and asked them questions about the percentage of their patient load that has a diagnosis of ABI. For those reporting that less than 10% of their caseload had an ABI diagnosis, 71% cited the complexity of the patient's needs as one of the major reasons.

The issue of staff training regarding ABI spans the continuum. Nurses and therapists in acute care and community hospitals identified the need for increased training to enable them to care appropriately for their ABI patients, particularly in relation to behaviours. Long-term care facilities identified the need for increased training for their staff if they are to successfully serve this population. Community organizations reported that the onus of educating staff about ABI lands with them, an issue that is not usually reflected in their budgets. This is of particular concern as the challenges of working with individuals with an ABI can result in staff burnout and turnover, exacerbating the burden on organizations to provide training.

A systematic response to these issues is needed to plan appropriately for the human resource requirements needed to support this population. This is true both within the ABI system service delivery as well as beyond it. Individuals with ABI are often living (whether temporarily or permanently) in environments that are not specialized to meet their needs, e.g., CCC beds, acute care beds or LTC facilities. While this is not ideal and improved options need to be developed, more training for nurses, therapists and other staff could mitigate crisis situations and improve the quality of life of individuals with ABI while they wait for more appropriate living environments.

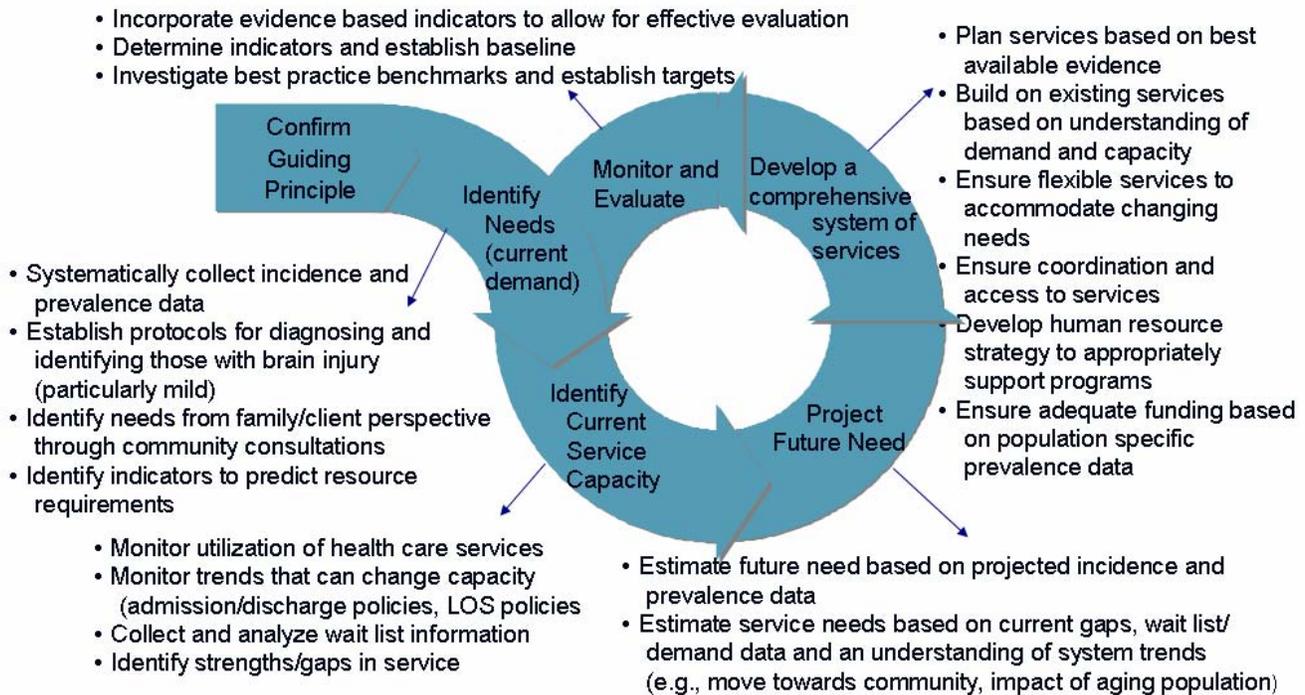
4.0 PLANNING FRAMEWORK / MODEL OF SYSTEM

In the course of this project, the team identified a number of critical steps that led to the creation of a framework for planning ABI services. The activities of the committee are reflected in this framework but its primary purpose is to provide a mechanism to monitor and plan for a system of ABI services on an ongoing basis.

The components of the planning framework are as follows:

A Framework for Effective Planning of ABI Services

Vision: to ensure accessible and comprehensive services for those living with the effects of an ABI



(See Appendix F for a full page version of this diagram)

Given systemic challenges, some of the recommended components of the planning framework may not be feasible but they were included to guide planners in the future development of ABI services and to highlight potential research needs. For example, it was identified that a valuable component of system planning would include the ability to systematically employ indicators to predict future service requirements. If we can reliably establish what service requirements are needed by those with moderate-to-severe brain injury (as measured by an injury severity rating) and we can project how many of Toronto’s estimated annual ABI incidences would be moderate-to-severe injuries, then we should be able to make projections about service requirements. This would depend on the identification and the consistent employment of reliable indicators and outcome measures, which currently do not exist within the ABI community.

The components of this diagram are described in more detail in the section that follows.

4.1 Confirm Guiding Principles

- Accessible: ABI services should be accessible to all persons who need them.
- Appropriate: Services and supports will be flexible, needs based, evidence based and targeted to take into account culture and beliefs, developmental stage, special needs and gender specific concerns. Services and supports will be provided in the least restrictive manner possible.
- Client/Family Centred: Every person with brain injury is a unique individual and the recovery path will be different for each person. Services and supports will be developed, delivered and evaluated in collaboration with persons with brain injury and their family.
- Seamless/Coordinated: Services should be provided in a seamless manner. Services and supports will be effectively coordinated and integrated with a focus on managing transitions effectively.
- Adequately Resourced: Services for people with ABI should be funded at a level which is sufficient to meet the needs of Toronto residents.
- Accountable: Persons with brain injury, their families, community groups, agencies, brain injury associations, ministries and others have a shared responsibility to ensure that prevention occurs, that services and supports for persons with brain injury and their families exist, and that the delivery of these services is managed effectively.

4.2 Identify Current Demand

- Systematically collect incidence and prevalence data:
 - Support the development and maintenance of the ABI database project currently funded through ONF;
 - Promote the consistent use of protocols for identifying brain injury (particularly with mild brain injury);
 - Enhance mechanisms for collecting data at emergency departments and doctors' offices.
- Identify needs from family/client perspective through community consultation.
- Identify and consistently employ indicators to predict resource requirements.

4.3 Identify Current Service Capacity

- Monitor utilization of healthcare services. This will require consistent reporting on standard indicators (e.g., discharges from acute care, admissions to inpatient rehab, admissions to outpatient/community rehab, LOS). The Toronto ABI Network is able to track much of this through the management of the centralized referral process; however, processes could be improved to better track those who are discharged from acute care who are not referred for rehabilitation and those who are accessing the wide range of community services in Toronto.
- Conduct environmental scans/surveys of program availability (in this project a single point in time survey was used to collect this information).
- Collect and analyze wait list information.
- Identify strengths/gaps in service.

4.4 Project Future Need

- Estimate future need based on projected incidence and prevalence data.
- Employ predictive model for resource planning once appropriate indicators are available and consistently used.
- Estimate service needs based on current gaps, wait list/demand data and an understanding of system trends (e.g., reduced LOS in acute care, move towards community based support, impact of aging population).

4.5 Develop System of Services/Programs

- Plan services based on best available evidence.
- Build on existing services based on an understanding of demand and capacity.
- Ensure flexible services to accommodate changing needs.
- Effectively monitor the system and facilitate flexible access, possibly through the incorporation of a case management/coordination role in service model.
- Develop human resource strategy to appropriately support programs (including training requirements, standards for staffing ratios).
- Determine adequate funding requirements based on population specific prevalence data.

4.6 Monitor and Evaluate

- Determine and employ indicators for evaluating the effectiveness of services and the overall system and establish baseline (e.g., wait times, satisfaction measures and measures of family/caregiver burden).
- Investigate best practice benchmarks and establish targets.

5.0 RECOMMENDED OPTIONS FOR THE FUTURE OF ACQUIRED BRAIN INJURY SERVICES IN TORONTO

5.1 Population-based Planning for People with Acquired Brain Injury in Toronto

The future of ABI services in Toronto is dependent on population-based planning. The Planning Committee recommends:

That planning for ABI services in Toronto take on a population-based approach rather than in response to individuals with ABI in crisis.

‘Population-based principles provide the scientific basis for action and the rationale for the formation of a defensible policy.’⁴³ Population-based planning needs to incorporate a clinical epidemiological perspective, evidence based practice, an emphasis on outcome and an emphasis on prevention,⁴⁴ each of which will need to be incorporated into the development of an ABI strategy such as outlined below in recommendation #3.

To undertake population based planning, the following activities will be required:

1. Systematically collect incidence and prevalence data.
2. Establish protocols for diagnosing and identifying those with brain injury (particularly mild brain injury).
3. Establish a process to monitor needs from family/client perspective through community consultation.
4. Identify appropriate outcome indicators to predict resource requirements following brain injury.
5. Monitor utilization of healthcare services and collect and analyze wait list information to ensure that available service delivery models are appropriate to meet need (may include systematic evaluation of service delivery in areas that are identified as ‘not currently meeting needs’ to develop appropriate and specific recommendations such as increased funding, changes to admission/discharge criteria, changes to average LOS, etc.)

Population-based planning is a common trend for all healthcare services, however, as the mechanisms to accurately collect and analyze incidence and prevalence data do not adequately exist for ABI, background work is required to begin this process. This work has already begun in the form of the ABI database that is being developed by the ONF initiative cited previously and anything that the community can do to support this work will serve to enhance the efforts of planners and service providers as they advocate for necessary system change.

The outcome of such a recommendation is that:

- the appropriate level of services is available for individuals with ABI.
- services are provided when required and not only at the crisis point for the person with the ABI.
- the continuum of care meets the needs of the people with an ABI and is a complete continuum with multiple access points.

5.2 Broad Spectrum of Flexible Programs that Meet the Complex Needs of People with Acquired Brain Injury in Toronto

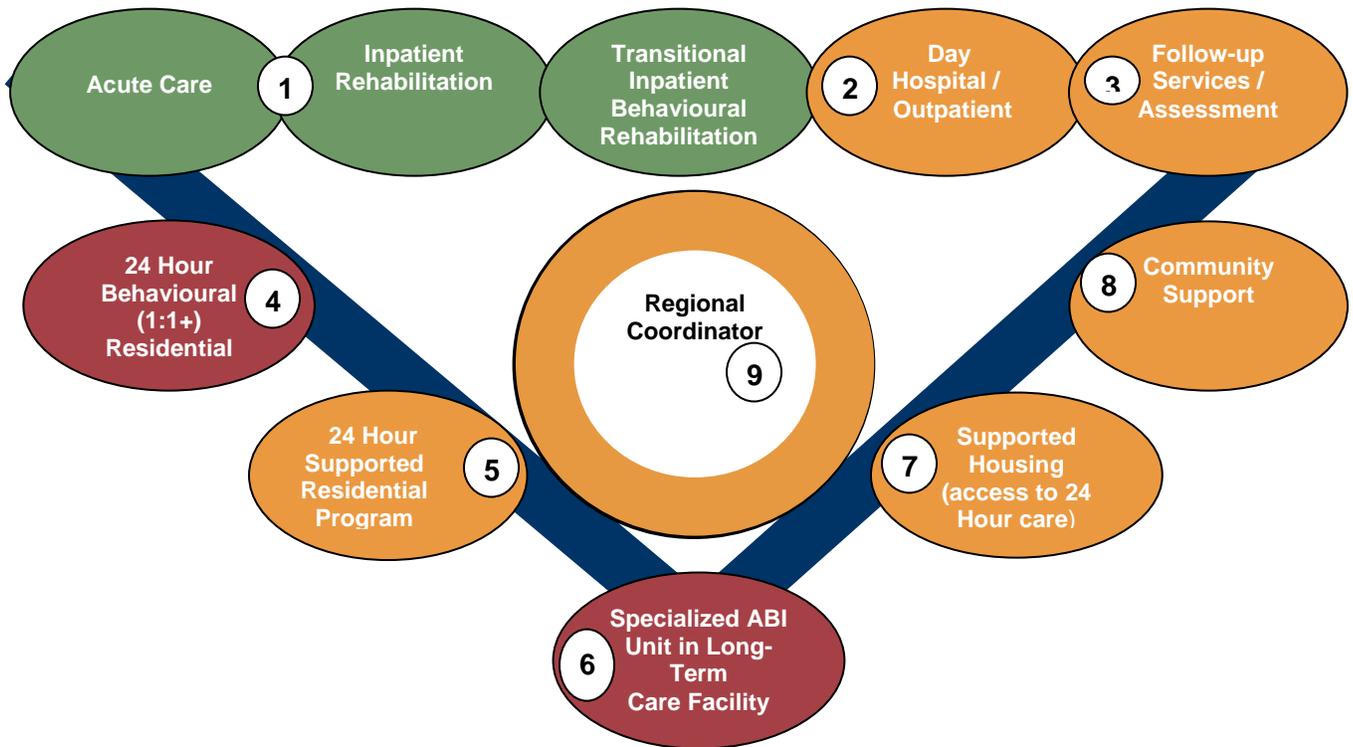
This report has demonstrated that there is a need to provide a broad spectrum of programs to meet the complex needs of people with an ABI. Some of these programs are already in existence and need enhancement while others are not available and need support to be developed. Therefore the Planning Committee recommends:

⁴³ Ibrahim, Michel A. et al (2001). “Population-Based Health Principles in Medical and Public Health Practice” *Journal of Public Health Management Practice*, 7 (3), 75-81

⁴⁴ Ibid.

That services be developed and appropriately funded to fill the gaps that currently exist in Toronto as depicted in the model below.

Model of Current and Proposed ABI Services in Toronto



①-⑨ see corresponding table below

Description of and Recommendations for Programs/Services that Currently Exist but Not In Sufficient Capacity or Do Not Currently Exist In Toronto

Please note that the descriptions in this table denote areas for change and do not provide a description of the range of services in that particular area (e.g., #8 refers to one enhancement that could be realized under the umbrella of community services, but is not meant to describe all available community services).

	Description	Client Profile	Status	Recommendation
1	<p>The transition point between acute care and inpatient rehabilitation.</p> <p>This transition point in the continuum works well for the majority of patients but for a select group it presents a challenge.</p>	<p>Individuals who require inpatient rehabilitation but are not able to be admitted either because there are no beds available or because they are not rehab ready.</p> <p>Often require continued nursing care and may require supervision due to cognitive and or behavioural issues.</p>	<p>Acute care facilities are under ongoing pressure to reduce average LOS and ensure patients are moved to the appropriate level of care as soon as possible.</p> <p>There is sometimes a disconnect between when the person is ready to leave acute care (i.e., medically stable) and when they are ready to be admitted to an inpatient rehabilitation program.</p> <p>This also complicates service delivery from the CCAC perspective as they are asked to begin providing rehab to individuals in the home while they wait for an inpatient admission. CCAC is being asked to respond quickly to provide rehabilitation to those who are waiting only to have the services disrupted, often in a matter of a few days, when the person is admitted to the rehab hospital.</p>	<p>Alternative options need to be available to ensure that people have access to the right level of care at the right time and that there is continuity of care.</p> <p>One possible option to be considered is step down or transitional care services.</p> <p>A comprehensive review of the service delivery model and the factors that create this barrier in patient flow will be required to develop an appropriate response.</p> <p>Attention needs to be given to the training requirements of nurses, therapists and other staff in various facilities to support them in dealing with patients with ABI while awaiting specialized services.</p>
2	<p>Day hospital/outpatient Clinic</p> <p>Often day hospital/outpatient therapies are the next step following inpatient services, however some people will access day hospital directly after acute care because they do not require an inpatient rehabilitation program.</p> <p>Therapies are provided on an outpatient basis approximately 1-3 times per week including physiotherapy, occupational therapy, speech language pathology, social work, psychiatry, psychology, nutrition services and psychiatry.</p>	<p>Individuals who require ongoing therapy following acute care and/or inpatient rehabilitation programs.</p> <p>Are able to access the clinic either independently or with the support of a third party (family, friend, support worker).</p>	<p>Specialized day hospital and outpatient clinic options are available for those with an ABI through Toronto Rehab, Bridgepoint Health and West Park Healthcare Centre.</p> <p>The waiting time for individuals to access the day hospital varies depending on the location and the therapy requested, however, in recent months it has consistently ranged from 6-8 weeks.</p> <p>There is concern that an ongoing delay in getting access to day hospital or outpatient therapies might encourage individuals to seek an admission to an inpatient program to avoid a disruption in their recovery, even in cases when this option is not indicated.</p>	<p>Investigate and establish best practice guidelines for clinically appropriate wait times for service (e.g., inpatient and day hospital).</p> <p>Investigate current demand and supply of day hospital services in Toronto to determine appropriate level of resources required to meet need within the established wait time guidelines.</p>

	Description	Client Profile	Status	Recommendation
3	<p>Follow-up clinics provide assessment and diagnostic evaluation for people post-hospitalization.</p> <p>Generally, assessments are led by physicians or psychiatrists and result in recommendations for service.</p> <p>Clinics provide a resource to community physicians for assessment, diagnosis of mild brain injury and treatment recommendations.</p>	<p>Individuals who require follow-up appointments to assess current functioning.</p> <p>Or individuals who require assessment for diagnostic and treatment recommendation purposes.</p>	<p>Follow-up is often provided by hospital that provided acute care or rehabilitation.</p> <p>Referrals from the community can be made to Sunnybrook & Women's College Health Sciences Centre's TBI Clinic and St. Michael's Hospital's Head Injury Clinic; however, Sunnybrook's criteria excludes people more than 3 months post-injury and the wait time for St. Michael's has been steadily growing over the past number of months (currently approximately five months).</p>	<p>Monitor demand and wait time for assessment, diagnostic and follow-up clinics to ensure appropriate and timely service response.</p>
4	<p>Highly resourced long-term residential program.</p> <p>24 hour 1:1 (or more) behavioural support. Secure environment, constant supervision.</p> <p>Significant clinical support.</p>	<p>Individuals with severe behavioural issues (e.g., physical aggression, self-injurious behaviours).</p> <p>Often a risk to themselves or others.</p> <p>May have dual diagnosis. Individuals with significant cognitive impairment.</p> <p>Individuals may also have physical impairment and/or medical issues such as unstable seizure disorders (not requiring significant nursing care).</p>	<p>Does not exist in Toronto.</p> <p>Programs do exist in other parts of the province that could be used as a model.</p>	<p>A comprehensive review of similar delivery models is required to determine the best model to meet the needs of Toronto and surrounding area.</p> <p>This will require input from provincial providers to determine demand. Program will need to be developed to meet the needs of Toronto residents, recognizing and accepting the necessity to support those from other regions where services do not exist.</p>
5	<p>Long-term residential program with 24 hour support and supervision.</p> <p>1:1 staffing for some activities throughout the day.</p> <p>Specialized clinical support.</p>	<p>Individuals with significant cognitive impairment.</p> <p>Individuals may have behavioural issues but must be able to be managed within a community setting.</p> <p>Not an ongoing risk to self or others.</p> <p>Individuals may also have physical impairment but are medically stable – no requirement for ongoing nursing.</p>	<p>Exists but wait lists are very long.</p> <p>Wait list for specialized ABI residential program is currently estimated at approximately 10 years.</p>	<p>Bring together community based providers to examine shared wait list issues and develop mechanisms for collaboratively monitoring and responding to demand (including advocating for additional resources where appropriate). This will require input from provincial providers. It should also include participation from service providers in other sectors (e.g., those funded under Ministry of Community and Social Services and mental health providers).</p> <p>A model of long-term support should also incorporate more options for families to receive the support required to keep the individual at home when this is the desired option and when it is a feasible and efficient use of resources.</p>

	Description	Client Profile	Status	Recommendation
6	<p>Unit within LTC Facility with specialized ABI resources.</p> <p>Provides age appropriate resources and environment.</p> <p>May need to be secure unit.</p> <p>Will require partnerships with ABI service providers including rehabilitation centres, community support providers and/or behavioural support.</p>	<p>Individuals with cognitive impairment.</p> <p>Individuals may also have physical impairment but are medically stable.</p> <p>May have moderate behavioural issues.</p> <p>Require supervision but not significant 1:1 support.</p>	<p>Does not exist in Toronto.</p>	<p>Conduct demonstration project for ABI program within LTC facility for older ABI residents with specialized needs.</p>
7	<p>Supported housing program with access to 24-hour support.</p> <p>Unsupervised time throughout day.</p> <p>Support for specific identified activities.</p>	<p>Individuals with moderate cognitive impairment.</p> <p>Able to access community independently.</p> <p>Individual may also have physical impairment but is medically stable – no requirement for ongoing nursing staff or attendant care.</p>	<p>Exists in Toronto but wait lists can be excessive.</p>	<p>See recommendation in row 5 of table.</p>
8	<p>Enhanced/modified model of case management to provide ongoing support following rehabilitation, to avoid crisis situations and to reduce requirement for costly residential placements.</p> <p>Supported by enhanced partnerships with other ABI providers, mental health providers and substance abuse providers.</p>	<p>Individuals with cognitive impairment, physical and/or behavioural issues but can access community independently.</p>	<p>Community providers in Toronto often provide case management as a component of service.</p> <p>For some the level of intensity available is not sufficient and the services cannot be flexible to accommodate a need for any significant increase in resources during crisis situations.</p> <p>Some programs offer more highly resourced and flexible community support but the wait list for this level of care is very long, often exceeding 2 years.</p>	<p>There is a project currently funded by the Ontario Neurotrauma Foundation that is looking at a demonstration project of this kind of service. Further recommendations may flow from this.</p>
9	<p>Regional Coordinator(s)</p> <p>Provides coordination of services to clients with an ABI in Toronto.</p> <p>Manages a central referral system to allow for a single point of access to rehabilitation and community support and ensure equitable access to services.</p> <p>Tracks and monitors referrals to ensure that no individuals are lost to the</p>	<p>All individuals with an ABI diagnosis in Toronto.</p>	<p>The Toronto ABI Network currently provides a central referral system that fulfills some of these objectives (i.e., ensuring single point and equitable access, tracking referrals and acting as a resource.)</p> <p>The role is currently funded to manage approximately 600 referrals annually with 0.5 FTE.</p> <p>There is no capacity at this time for the Regional Coordinator to provide direct support to those who have difficulty accessing appropriate services in the form</p>	<p>Enhance the role that the Regional Coordinator can take in facilitating and negotiating services for those individuals unable to access appropriate resources, particularly those who are considered difficult to serve within traditional models and those with dual diagnosis.</p> <p>Establish processes and ensure available resources to allow the Regional Coordinator to follow-up with patients who have been discharged without rehabilitation or who have declined rehabilitation.</p>

Description	Client Profile	Status	Recommendation
<p>system and that a transfer to the appropriate service is always documented.</p> <p>Acts as a resource to ABI providers, clients and families, and the community regarding availability of and access to ABI resources.</p> <p>Provides a forum for problem solving and negotiating support for individuals having difficulty accessing appropriate services.</p> <p>Provides a mechanism to ensure that all individuals treated for a brain injury in Toronto are identified and advised of potential resources.</p>		<p>of advocacy and negotiation for resources.</p> <p>In addition, the Toronto ABI Network is only able to provide information and resources to those who are referred to them and there is evidence that a number of individuals are being discharged from acute care without specialized ABI support or follow-up.</p> <p>The Toronto ABI Network is not made aware of the individual because a referral to rehabilitation is not deemed necessary and the individual and family may not be made aware of whom to contact in the event that they do require support later.</p>	<p>Establish mechanisms to ensure that individuals are referred to the Regional Coordinator even when they are being discharged without ABI services to allow for follow-up and to ensure they are aware of the mechanisms to re-enter the system if services are required.</p> <p>Based on our understanding of demand and in considering the resourcing of similar programs, it is anticipated that one Regional Coordinator per LHIN would be appropriate. In Toronto, where there are 5 LHINs, the Regional Coordinators should be centralized within a single infrastructure. Provincially, the Regional Coordinators need to be connected, sharing resources and information in a deliberate and regular fashion.</p>

Principles

To meet the needs of people with an ABI, these services must:

- Recognize that ABI can be a chronic health concern and many individuals require life-long support.
- Enable people with ABI to enter and re-enter the system at various points in their lives/stages of recovery.
- Be coordinated and managed so that people with an ABI do not fall through the cracks once active rehabilitation/therapy is no longer being sought.
- Ensure services to people with ABI are available throughout the duration of the person's life and not only during a crisis or when the ABI occurs.
- Recognize that many with cognitive and/or behavioural challenges require life-long residential options to meet their needs and these services must be available at different levels to accommodate the varied and changing needs of those with ABI. Such a model would allow for movement through the system.
- Facilitate transition across the continuum and between services (including between pediatric and adult based services).
- Be integrated with the healthcare system to enable people with ABI who are faced with additional healthcare needs to be served appropriately (e.g., those with dual diagnosis).
- Include new and multifaceted services to meet the broad healthcare needs of people with ABI, for example people with the following needs: vocational and academic support, appropriate community support and case management, supported housing.

To ensure the sustainability and responsiveness of this service and support model, the Planning Committee recommends that the mechanisms of funding be appropriate to the model described above. This does not always mean new funding. In some cases, flexibility of funding is what is needed to enable new and innovative programs to be developed. As an example, if the community based programs were able to direct funding in a more flexible manner, they may be able to provide a more responsive service which can ensure that the appropriate level of care is provided at the appropriate time, again allowing for flow through the system.

5.3 Development of an Acquired Brain Injury Strategy

Through the process of conducting this epidemiological and system review, the committee identified a number of specific recommendations that reflect the importance of the guiding principles and provide a starting point for bridging the gap between the identified demand for services and Toronto's current capacity to respond. These specific recommendations are outlined below. To maximize their impact however, they need to be considered in the context of wider system change.

Providing specific recommendations to address identified regional need will move the system forward but will not provide a mechanism to ensure that the system continues to evolve as needs and our healthcare environment change. The planning framework presented earlier in this document provides part of the solution in terms of the monitoring required to understand supply and demand and the mechanisms to plan accordingly.

However, to ensure an integrated model of services and support that is responsive, appropriate and sustainable over the long-term it is considered necessary:

For the community of providers in Toronto and in Ontario to engage in the development of a comprehensive ABI strategy, similar to those that have been developed for other health populations.

The recommendations below can form parts of a system-wide strategy but further work is required to improve functional outcome following a brain injury, improve the quality of life of those living with the effects of a brain injury and to optimize resource utilization. It is recommended that the work to develop a coordinated strategy take both a provincial and a regional focus and draw on the influence of key champions to advocate and move the system forward.

At a minimum, such an initiative should involve a committed effort from representatives of the following:

- Local Health Integration Networks
- individuals living with a brain injury
- healthcare providers (private and public) (pediatric and adult)
- researchers
- mental health providers
- insurance sector
- legal sector.

This initiative will require a dedicated and multi-year commitment if a comprehensive plan is to be developed.

A full strategy will require consideration and a strategic approach in the following areas:

- public awareness and prevention
- emergency and acute care
- rehabilitation
- supported independent living
- LTC and community support
- family support and caregiver support
- human resources
- educational requirements for health professionals
- research, e.g., implications of aging ABI population
- monitoring and evaluating outcomes.

6.0 CONCLUSION

This initiative has illustrated the current system of ABI service and support delivery in Toronto, highlights issues and makes recommendations for future development. It also provides a starting point for the development of an ABI strategy by identifying some of the components that will need to be included in a comprehensive plan. It is the hope of the Planning Committee that the recommendations within this document will provide planners and funders with the information necessary to improve the lives of those with ABI by streamlining their access to appropriate services and supports.

It is our belief that the implementation of the stated recommendations will:

- Create a more comprehensive system of service and support delivery that will be flexible and responsive to changing needs.
- Improve access to support for those with ABI and their families through a better understanding of patient need and service capacity.
- Provide a catalyst for the development of a coordinated ABI strategy.

Finally, it is anticipated that the findings and recommendations within this document are mirrored in other communities across the province of Ontario.

APPENDIX A: Committee Members

Hedy Chandler (<i>chair</i>)	Executive Director, Community Head Injury Resource Services of Toronto
Heather Brien	Executive Director (Acting), Toronto ABI Network / Clinical Service Manager, Toronto Community Care Access Centre, ABI Program
Debra Carew	Director of Operations, Trauma Program, Sunnybrook & Women's College Health Sciences Centre (Sunnybrook Campus)
Barbara Cawley	Manager, ABI Program, COTA Health
Kathi Colwell	Program Director, Musculoskeletal and Neuro Rehabilitation, Bridgepoint Health
Dr. Monica Gemeinhardt	Manager, Outpatients & Neurorehabilitation Program, Bloorview Kids Rehab*
Dr. Gary Gerber	Clinical Director, ABI Behaviour Service, West Park Healthcare Centre*
Lynn Guerriero	Manager, Program Services, Brain Injury - Neuro Cognitive, Toronto Rehab*
Charissa Levy	Executive Director, Toronto ABI Network
Alicja Michalak	Case Manager, Head Injury Trauma & Neurosurgery, St. Michael's Hospital
Judy Moir (<i>author</i>)	Assistant Executive Director, Toronto ABI Network
Linda Novotny	Director, Programs, West Park Healthcare Centre

* has changed position and/or organization subsequent to their involvement with this initiative

Toronto District Health Council Staff

Hindy Ross	Health Planner and Project Consultant
Cynthia Damba	Epidemiologist
Carley Hay	Epidemiologist
Leslie Sorensen	Senior Health Planner

We would also like to thank the following for their feedback and support:

The Toronto ABI Network Advisory Committee

Stella Bester, Intake Coordinator & Regional Director, Hamilton Health Sciences, ABI Program

Warner Clarke, Program Consultant, CCAC Branch, Ministry of Health and Long-Term Care

Dr. Carolyn Lemsky, Clinical Director, Community Head Injury Resource Services of Toronto

Patty Aird, Toronto ABI Network

Robert Jessop, Toronto ABI Network

Linda Milan, GTA Rehab Network

APPENDIX B: Definition of Acquired Brain Injury

Appendix B1

Congenital Development Problems:

(not considered ABI)

- Cerebral Palsy
- Autism (Pervasive Developmental Disorder)
- Developmental Delay
- Down's Syndrome (21 Chromosomal Abnormalities)
- Spina Bifida with Hydrocephalus
- Muscular Dystrophy

Progressive Processes/Diseases:

(not considered ABI)

- Alzheimer's Disease
- Pick's Disease
- Dementing Processes
- Amyotrophic Lateral Sclerosis
- Multiple Sclerosis
- Parkinson's Disease and Similar Movement Disorders
- Huntington's Disease

Appendix B2

Non-traumatic Causes of ABI:

- Anoxia
- Aneurysm and Vascular Malformations
- Brain Tumours
- Encephalitis
- Meningitis
- Metabolic Encephalopathies
- Stroke with Cognitive Disabilities *(eligibility for service may depend on client' needs/goals)*

NOTE:

This definition for 'acquired brain injury' (or 'ABI') was developed by the Clinical Data Working Group of the Toronto ABI Network and adopted by the Advisory Committee.

As part of developing consensus, several drafts of the definition were distributed to clinicians and professionals in the ABI field to ensure that it is clear, accurate and addresses the issues.

APPENDIX C: Project Charter

1.0 Background

1.1 Introduction

The Toronto Acquired Brain Injury Network began in 1995 to enhance access to and coordination of ABI services. Over the past few years the Network has been tracking clients who are in need of service but unable to access the resources necessary to meet these needs. Through this tracking, the Network has identified that further planning in Toronto around community based ABI services is required.

The Toronto ABI Network alerted the Toronto Region of the Ministry of Health and Long-Term Care (Ministry) to this requirement, specifically highlighting the lack of services for those with behavioural needs. At the same time, the Network contacted the Toronto District Health Council (TDHC) to request assistance with planning for long-term ABI service in Toronto.

1.2 Rationale

Historically, there has been very little long-range planning in Toronto for ABI services, in part due to the lack of enablers to capture data. Services to the ABI population began in 1978 when the first transitional group home in North America for adults with ABI opened up in Toronto. Ashby House was then a small program that over the years became the multi-service ABI agency known as Community Head Injury Resource Services (CHIRS). In 1987 funding was provided to Hugh MacMillan Centre to provide ABI services for children. Aside from these two services, it was not until the early in 1990s that the Ministry determined it would be cost-effective to develop the infrastructure for more community supported independent living and long-term residential programs, as well as respite and day programs. Much of this was developed in order to repatriate the people with ABI who were being sent to the United States for care⁴⁵.

Since this time, minimal additional planning around future needs of those with ABI has been undertaken. The result is some ABI populations have adequate services while others, such as those with behavioural problems, have limited services.

The number of people requiring ABI services has drastically increased for a variety of reasons, including: technology as an enabler for people to live longer with such conditions and an increasing proportion of young ABI clients who live a full life span. Furthermore, it has been difficult to calculate the exact incidence and prevalence of ABI as a clear diagnosis is not always made.⁴⁶ This complicates the ability to plan for comprehensive services.

Current hospital-based services are funded under the global budgets and therefore are not secure as hospital directions change. Community-based programs, on the other hand, receive “dedicated” funding for this population, however, these services are not provided around the clock and many clients are not receiving the level of care they require.⁴⁷

To overcome this gap in the system, the TDHC will develop a framework that will outline strategies for addressing current needs for people with ABI in Toronto through a committee of key stakeholders and utilization and population analyses.

⁴⁵ Carolyn Sherk Consultants, “A Continuum of Opportunity for People in Ontario with Acquired Brain Injury”, *Carolyn Sherk Consultants, Prepared for the Continuum of Opportunity Task Force*, December 1994

⁴⁶ Toronto District Health Council, “TDHC Multi-Year Plan: 2000-2003 LTC Populations”, *Toronto District Health Council*, February 2000

⁴⁷ Toronto District Health Council, “TDHC Multi-Year Plan: 2000-2003 LTC Populations”, *Toronto District Health Council*, February 2000

2.0 Project

2.1 Objectives of the Project

- To develop a Toronto-level framework for developing ABI services with strategies for addressing current and future needs of people with ABI (See Appendix A).
- To more clearly identify incidence and prevalence rates of ABI as well as projected rates to assist in planning for future ABI services.

2.2 Scope of the Project and Key Elements

Key elements of the project will include:

- Creating a profile of ABI clients (for all ages) including incidence, prevalence and future projections (see attached Proposal for Data Analysis Component of ABI Project).
- Defining utilization patterns including population served, type of care delivered, future demographics and referral patterns.
- Consultation with current referring agencies and providers to determine resources required to provide services and bridge gaps in current services.
- Analysis of data to assist in strategic planning for the future needs of people with an ABI.

2.3 Management of the Project

The TDHC will develop the project in consultation with:

- Ministry of Health and Long-Term Care, Toronto Region
- Secretariat of the Toronto Acquired Brain Injury Network.

A project advisory group will be struck that comprises representative providers including:

- Toronto Acquired Brain Injury Network
- Bridgepoint Health
- Toronto Rehabilitation Institute
- West Park Healthcare Centre
- Community Head Injury Resource Services of Toronto
- Toronto Community Care Access Centre, ABI Program
- COTA Health
- Other providers of ABI services
- Other potential providers of ABI services

3.0 Action Plan

3.1 Key Milestones

Key Milestone	Oct 04	Nov 04	Dec 04	Jan 05	Feb 05	Mar 05
Confirm Project Charter						
Background Research/Data Collection						
Consultations with Key Stakeholders						
Final Report						

4.0 Supporting Resources

DHC staffing resources are to include a health planner and an epidemiologist.

APPENDIX D: ICD-9 & ICD-10 Codes**I. Traumatic Causes**

Diagnosis	ICD-9 Code and Description	ICD-10 CA Code and Description
1. Fracture of the skull with loss of consciousness	800 – Skull	S02.0 – Skull
	801 – Base of skull	S02.1 – Base of skull
	803 – Other and unqualified skull fractures	S02.9 – Skull and facial bones
	804 – Multiple fracture, involving face and other bones	S02.7 – Multiple fractures involving skull and facial bones
2. Intracranial injury, excluding those with skull fracture	850 – Concussion	S06.0 – Concussion
	851 – Cerebral laceration and contusion	S06.2 – Diffuse brain injury
	852 – Subarachnoid, subdural and extradural hemorrhage	S06.4 – Epidural Hemorrhage S06.5 – Traumatic subdural hemorrhage S06.6 – Traumatic subarachnoid hemorrhage
	853 – Other and unspecified intracranial hemorrhage following injury	S06.8 – Other intracranial injuries
	854 – Intra-cranial injury of other and unspecified nature	S06.1 – Traumatic cerebral edema S06.3 – Focal brain injury S06.9 – Intracranial injury, unspecified S09.7 – Multiple injuries of head S09.8 – Other unspecified injuries of head S09.9 – Unspecified injury of head
3. Open wound of head, neck and trunk	873.0 – Scalp, without mention of complication	S01.0 – Open wound of scalp S08.0 – Traumatic amputation of part of head
	873.9 – Other and unspecified open wound of head without mention of complication	S01.7 – Multiple open wounds of head S01.8 – Open wounds of other parts of head S01.9 – Open wound of head, part unspecified
4. Late effects of injuries, poisonings, toxic effects and other external causes	905.0 – fracture of skull and face bones	T90.2 – Sequelae of fracture of skull and facial bones
	907.0 – intracranial injury without mention of skull fracture	T90.5 – Sequelae of intracranial injury T90.9 – Sequelae of unspecified injury of head
5. Certain traumatic complications and unspecified injuries	959.0 – Injury, other and unspecified	S09 – Other and unspecified injuries of head S197 – Multiple injuries of neck S198 – Other specified injuries of neck S199 – Unspecified injury of neck

ICD-10 codes recommended by CDC for traumatic brain injury (Note: not all of these included in the above table):

- S01.0 – S01.9: Open wound of head
- S02.0-S02.1, S02.3, S02.7 – S02.9: Fracture of skull and facial bones
- S06.0, S06.2-S06.9 – Intracranial injury
- S07.0-S07.1, S07.8-S07.9 – Crushing injury of head
- S09.7-S09.9 – Other unspecified injuries of head
- T01.0: Open wounds involving head and neck
- T02.0: Fractures involving head and neck
- T04.0: Crushing injuries involving head and neck
- T06.0: Injuries of brain and cranial nerves with injuries of nerves and spinal cord at neck level
- T90.1-T90.2, T90.4-T90.5, T90.8-T90.9: Sequelae of injuries of head

II. Non-Traumatic Causes

Diagnosis	ICD-9 Code and Description
1. Toxic effects of substances, chiefly non-medical as to source	980 – Toxic effect of alcohol 985 – Toxic effect of other metals 986 – Toxic effect of carbon monoxide
2. Complications of surgical and medical care, not elsewhere classified	997.0 – Nervous system complications (possibly includes the brain damage related to chemotherapy and radiation) (codes included are: 997.0 – Nervous system unspecified; 997.01- Central nervous system complications (anoxic brain damage and cerebral hypoxia); 997.02 – Iatrogenic cerebrovascular infarction or hemorrhage; 997.09 – other nervous system complications)
3. Anoxia	348.1 – Anoxic brain damage (includes all causes of anoxia except those occurring following abortions, ectopic pregnancy, labour and delivery and newborn) 997.0 – Nervous system complications (complications of surgical and medical care, not elsewhere classified. 997.01 = Nervous system complications [anoxic brain damage and cerebral hypoxia]) – see above section 994.1 – Drowning and nonfatal submersion 994.7 – Asphyxiation and strangulation
4. Aneurysm and vascular malformations	430 – Subarachnoid hemorrhage 431 – Intracerebral hemorrhage 432.1 – Subdural hemorrhage 432.9 – Unspecified intracranial hemorrhage
5. Brain tumours	191 – Malignant neoplasm of brain 198.3 – Secondary malignant neoplasm of brain and spinal cord 225.0 – Benign neoplasm of brain 225.2 – Benign neoplasm of cerebral meninges 237.5 – Neoplasm of uncertain behaviour – brain and spinal cord 237.6 – Neoplasm of uncertain behaviour – meninges 239.6 – Neoplasm of unspecified nature – brain
6. Encephalitis	046.2 – Subacute, sclerosing encephalitis 054.3 – Herpetic meningoencephalitis 055.0 – Postmeasles encephalitis 062.0 – Japanese encephalitis 062.2 – Eastern equine encephalitis
7. Metabolic encephalopathies	250.3 – Diabetes with other coma 251.0 – Hypoglycemic coma 310.2 – Post-concussion syndrome
8. Meningitis	324.0 – Intracranial abscess 324.9 – Intracranial and intraspinal abscess of unspecified site 348.0 – Cerebral cysts

APPENDIX E: Data Tables

Table 2: Length of Stay (LOS) and Average Length of Stay (ALOS) for Non-Traumatic Brain Injury Separations from Acute Care Toronto Hospitals by Age Group and Gender, 2001/2002				
Age Group	Data	Female	Male	Overall Total
0-9	Separations	132	157	289
	LOS	1,055	1,484	2,539
	ALOS	8.0	9.5	8.8
	ALC	0	35.0	35.0
10-14	Separations	36	44	80
	LOS	401	445	846
	ALOS	11.1	10.1	10.6
	ALC	1.0	0	1.0
15-18	Separations	38	23	61
	LOS	348	337	685
	ALOS	9.2	14.7	11.2
	ALC	25.0	30.0	28.3
19-24	Separations	40	49	89
	LOS	410	315	725
	ALOS	10.3	6.4	8.1
	ALC	6.8	15.0	10.3
25-44	Separations	435	434	869
	LOS	5,344	5,463	10,807
	ALOS	12.3	12.6	12.4
	ALC	20.0	36.0	29.9
45-64	Separations	1,023	1,259	2,282
	LOS	13,154	15,962	29,116
	ALOS	12.9	12.7	12.8
	ALC	30.8	57.8	45.8
65-74	Separations	816	926	1,742
	LOS	11,215	13,774	24,989
	ALOS	13.7	14.9	14.3
	ALC	21.9	29.6	26.1
75+	Separations	860	926	1,786
	LOS	12,463	12,547	25,010
	ALOS	14.5	13.5	14.0
	ALC	38.9	34.3	36.8
Unknown	Separations	0	0	0
	LOS	0	0	0
	ALOS	0	0	0
	ALC	8.5	0.0	8.5
Total	Separations	3,380	3,818	7,198
	LOS	44,390	50,327	94,717
	ALOS	13.1	13.2	13.2
	ALC	30.8	39.7	35.5

Source: Provincial Health Planning Database, 2004

Table 3: Number and Percentage of Traumatic Brain Injury Separations in Toronto Hospitals, Stratified by Age Group, 2001/2002

Age Group	Number of Separations	%
0-9	234	10.7
10-14	85	3.9
15-18	125	5.7
19-24	176	8.0
25-44	449	20.5
45-64	428	19.6
65-74	260	11.9
75+	432	19.7
Total	2,189	100.0

Source: Provincial Health Planning Database, 2004

Table 4: Number and Percentage of Traumatic Brain Injury Separations in Toronto Hospitals, Stratified by Entry Description, 2001/2002

Entry Code	Description	Number of Separations	Percentage
E	Emergency department.	2,005	91.6
D	Direct to unit via admitting dept.	178	8.1
C	Via a clinic in reporting institution	4	0.2
P	Via day procedure/surgery dept.	2	0.1
Total		2,189	100.0

Source: Provincial Health Planning Database, 2004

Table 5: Non-Traumatic ABI Separations from Acute Care Toronto Hospitals, by Discharge Disposition, 2001/2002

Discharge Disposition Description	Number of Separations	Percentage
Discharged	5,789	80.4
Deceased	1,367	19.0
Signed out	42	0.6
Total	7,198	100.0

Source: Provincial Health Planning Database, 2004

Table 6: Discharges Due to Traumatic ABI from Emergency Departments of Toronto Hospitals, by Visit Disposition Code, 2001/2002

Visit Disposition Code Description	Number	Percentage
Admitted as inpatient (in own facility)	665	4.6
Admitted as inpatient to critical care unit/operating room (in own facility)	282	2.0
Client left against medical advice/refused treatment	561	3.9
Client not seen by any healthcare provider	95	0.7
Dead on arrival	3	0.0
Death after arrival / death in emergency	15	0.1
Discharged to place of residence	12,561	87.6
Transferred to another facility (acute/other)	121	0.8
Transferred to clinic (in own facility)	15	0.1
Transferred to day surgery (in own facility)	5	0.0
Transferred to emergency (in own facility)	9	0.1
Total	14,332	100.0

Source: Provincial Health Planning Database, 2004

Table 7: Referrals Received by the Toronto ABI Network, January 1, 2003 - December 31, 2003

REFERRAL FROM	SERVICE REQUESTED				
	Inpatient ABI rehab	Ambulatory care	Community	Other	Total
Acute care	349	34	22	1	406
Inpatient ABI rehab	6	26	53	0	85
Ambulatory care	0	4	10	0	11
Community support	2	6	22	0	30
Other	14	11	19	0	44
TOTAL	371	78	126	1	576
PERCENTAGE	64.41	13.54	21.88	0.17	100.00

Source: Toronto ABI Network Database

Table 8: Referrals Received by the Toronto ABI Network, January 1, 2004 - December 31, 2004

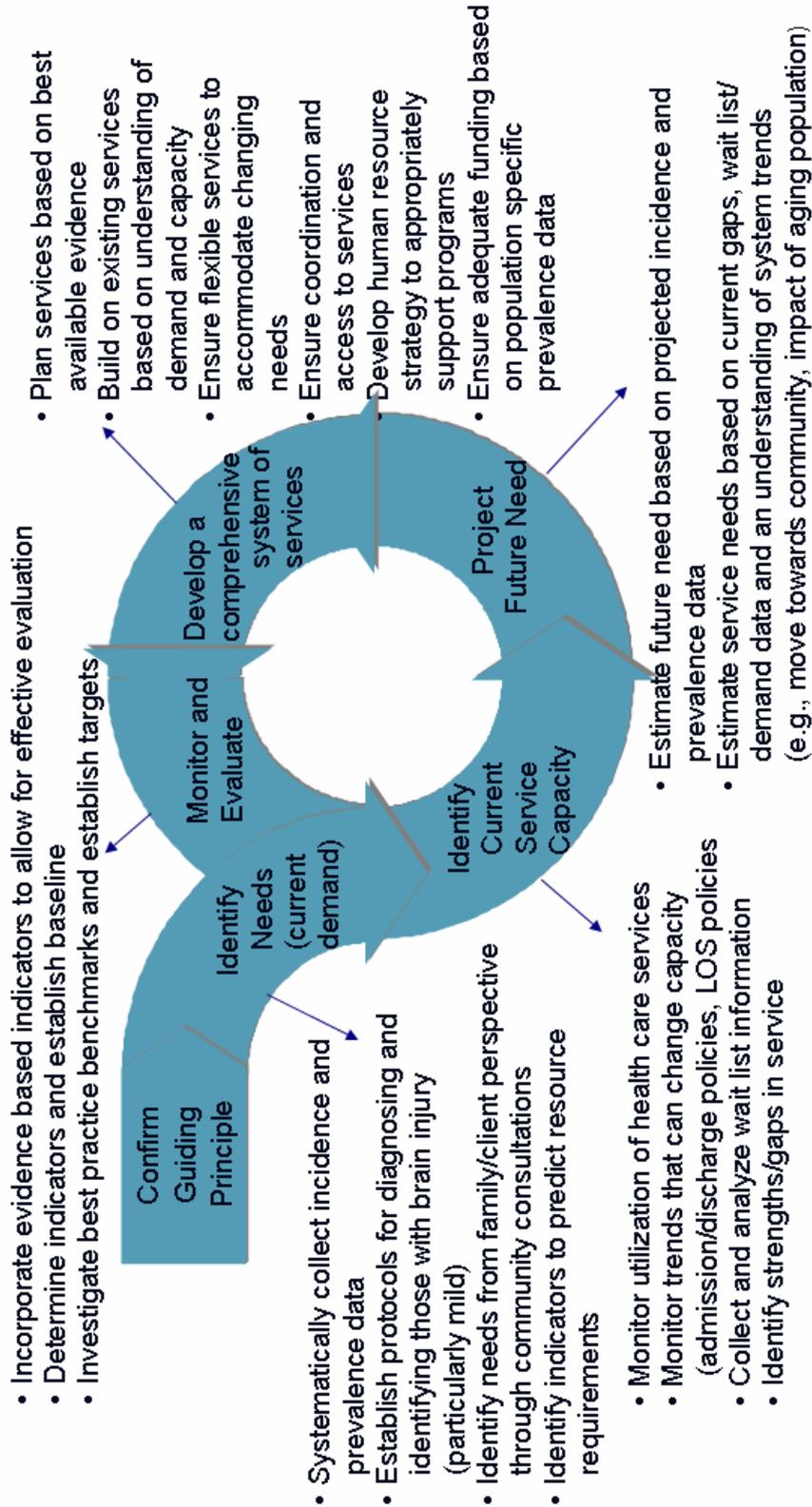
REFERRAL FROM	SERVICE REQUESTED				
	Inpatient ABI rehab	Ambulatory care	Community	Other	Total
Acute care	440	25	7	1	473
Inpatient ABI rehab	8	35	62	0	105
Ambulatory care	1	2	18	0	21
Community support	2	6	18	0	26
Other	15	17	40	0	72
TOTAL	466	85	145	1	697
PERCENTAGE	66.86	12.20	20.80	0.14	100.00

Source: Toronto ABI Network Database

APPENDIX F: Planning Framework/Model of System

A Framework for Effective Planning of ABI Services

Vision: to ensure accessible and comprehensive services for those living with the effects of an ABI



APPENDIX G: Provider Survey Questions

ABI Program Survey Instructions

This is a two-part survey for members of the Toronto ABI Network. The first step is to correct the information on the fact sheet on the Network's website. A copy of this fact sheet is in this package. The second step is to fill out the following survey.

One fact sheet and one accompanying survey should be completed for every program the organization has for ABI clients/patients.

Part A: Answer the following question based on the services provided through this particular program to the client or patient.

1. Program Services

Please check off all services provided by the program

Occupational Therapy_____	Physical Therapy_____
Social Work Services_____	Medical Treatment_____
Speech Language Pathology Services_____	Recreational Therapy_____
Vocational Services_____	Educational Services_____
Family Support_____	Home Making_____
Personal Support_____	Nursing Care_____
Case Management_____	Psychology_____
Neuropsychology_____	Psychiatry_____
Life Skills_____	Rehabilitation Support_____
Behavioural Therapy_____	Community Support_____
Pediatrics_____	
Other (specify) _____	

Part B: The following questions should be answered by looking at current clients/patients in the program. This is a snapshot of who is currently in the program. Acute inpatient programs should only look at those with a TBI. All other programs should look at TBI or non-traumatic as specified by the program.

1. Client Profile (snapshot of current clients)

Please fill in the following questions with data as at March 2005

- a. Age (indicate the number of clients in the following age categories)
7 days-9 years_____ 10-18 years_____
19-24 years_____ 25-44 years_____
45-64 years_____ 65-74 years_____
75 years and over_____
- b. Sex (indicate the number of current clients who are male or female)
Male_____ Female_____
- c. Cause of Injury (indicate the number of current clients with the following)
Fall_____ MVC_____ Aneurysm_____ Tumour_____ Anoxia_____ Infection_____
Other (specify) _____

- d. Severity of ABI (indicate the number of patients/clients)
mild____ moderate____ severe____

Please indicate which scale you used to respond to this question: _____

- e. Indicate the number of clients with:
One comorbidity____ Two comorbidities____
Three or more comorbidities____
- f. Co-morbidities (indicate the number of current clients with the following):
Physical disability____ Substance abuse____
Mental illness____
Chronic illness (specify) _____
Other (specify) _____
- g. Current Living Situation (indicate number of clients living in the following):
Home____
Home with full-time caregiver support____
Complex Continuing Care____
Long-Term Care facility____
Supportive housing____
Other (specify) _____
- h. Client Referral Source (indicate the number of clients referred from the following)
Family physician____ Emergency room____
Hospital____ Community agency____
Self referral/family____
Other (specify) _____
- i. Client Municipality of Residence (indicate the number of clients from each area)
Toronto____ Peel____ York Region____
Durham____ Outside GTA in Ontario____
Outside Ontario in Canada____ Outside Canada____

2. Wait List Information

- a. Do you have a wait list?____
- b. If yes, number of people on the wait list____
- c. Average waiting time____
- d. Please specify how average wait time is calculated (e.g. from referral or from acceptance into program)_____
- e. Point at which you place a client onto a wait list
Once approved for program____
Time of referral____
Other (specify) _____
- f. How is your wait list prioritized (e.g., do referrals from a hospital get priority):

- g. Reason for wait (e.g., needs too severe, staff vacancies, etc.)

- h. Are your clients/patients receiving care from any other ABI provider? _____
If so, which provider? _____

3. Human Resource Information

Indicate the number of FTEs currently working in the program for the following occupations

Occupational Therapists _____	Physiotherapists _____
Physicians _____	Social Workers _____
Nurses _____	Pediatricians _____
Psychiatrists _____	Neuropsychiatrists _____
Community Support Workers _____	Behavioural Therapists _____
Child & Youth Workers _____	Rehabilitation Support Workers _____
Speech Language Pathologists _____	Personal Support Workers _____
Recreationists _____	Psychologists _____
Neuropsychologists _____	Case Managers _____
Other (specify) _____	

Part C: The following questions should be answered using year end data from 2003/2004.

1. Client Profile (2003/2004)

Please fill in the following using year end data from 2003/2004. If question does not apply to your organization, please fill in N/A.

- Number Male Clients _____
- Number Female Clients _____
- Number of Admissions to the Program _____
- Number of Discharges _____
- Average LOS _____
- Number of Patient Days _____
- Duration of the Service _____
- Number of Visits _____
- Number of Attendances _____
- Average Age _____
- Range of Ages _____
- Number of clients whose home address is the in the following areas:
 - Toronto _____
 - GTA (outside Toronto) _____
 - Outside GTA (in Ontario) _____
 - Canada (outside Ontario) _____
 - Outside Canada _____

2. Human Resource Information

Indicate number of actual FTEs for the program in 2003/2004 for the following occupations

Occupational Therapists_____	Physiotherapists_____
Physicians_____	Social Workers_____
Nurses_____	Pediatricians_____
Psychiatrists_____	Neuropsychiatrists_____
Community Support Workers_____	Behavioural Therapists_____
Child & Youth Workers_____	Rehabilitation Support Workers_____
Speech Language Pathologists_____	Personal Support Workers_____
Recreationists_____	Psychologists_____
Neuropsychologists_____	Case Managers_____
Other (specify) _____	

APPENDIX H: Key Informant Interview Questions

1. What would you consider the top five barriers to accessing services for people with an ABI living in Toronto?
2. What are some of the systemic problems that currently exist in Toronto with respect to ABI services? Are there examples from other jurisdictions that can act as quick fix or long-term solutions to these problems? Are there examples from other jurisdictions that can act as goals for where we should be heading with respect to ABI services in Toronto?
3. What are the future trends in service delivery with respect to ABI?
4. If you had to make one overall recommendation with respect to how to improve the system for people living with ABI, what would it be? If funding is the recommendation, where would you direct it?
5. The Ministry improved access to brain injury services recently by funding ABI services through community organizations. This step will offset the one-off requests of support for people living with ABI. Can you provide some perspective about how the ABI community can stem this type of issue in order to respond before it becomes a crisis?
6. We know that there is greater demand for certain services right now than others, could you speak to some of the gaps in service and given the demand, which services should a planning framework focus its attention on with respect to increasing or improving supply?
7. Given that Toronto serves many people from outside the city, would a recommendation to improve services outside of Toronto decrease the demand on services in Toronto? Would this be a significant decrease and if so, would there still be a necessity to increase supply of services in Toronto?
8. Any other thoughts or comments you feel are important for a report designed to act as a planning framework for the future of ABI services in Toronto?

APPENDIX I: Bibliography

ACMS DHC (2002), "Final Report of the ABI Working Group: A sub-committee of the Algoma LTC Committee"

Bloom, et.al. (2001), "lifetime and Novel Psychiatric Disorders After Pediatric Traumatic Brain Injury", *Journal of the American Academy of Child and Adolescent Psychiatry*

Boschen, K., et. al. (2005) "Identification of Best Practices in Reducing Stress and Burden for Family Caregivers of Persons with an Acquired Brain Injury". Unpublished.

British Columbia Ministry of Health (2002), "Guidelines for Planning Brain Injury Services and Supports.

Canadian Institute for Health Information (2004), "Ontario Trauma Registry Analytic Bulletin: Major Head and Spinal Cord Injury Hospitalizations in Ontario 2001-2002".

Canadian Institute for Health Information (2002). Provincial Health Planning Database. Toronto
<http://secure.cihi.ca/cihiweb/splash.html>

Centre for Disease Control (2004), "Traumatic Brain Injury in the United States: Emergency Department Visits, Hospitalizations, and Deaths" http://www.cdc.gov/ncipc/pub-res/TBI_in_US_04/TBI_ED.htm

Central West Health Planning Information Network (2002), "The Burden of Acquired Brain Injury",
www.cwhpin.ca

Cope, N., et.al. (2005), "Development of Systems of Care for Persons with Traumatic Brain Injury", *Journal of Head Trauma Rehabilitation*, 20(2).

Cusick, et.al. (2003). "Evaluation of the home and community-based services brain injury Medicaid Waiver Program in Colorado". *Brain Injury*, 17(11) 931-945

Davis, et.al. (2003), "Crisis and its assessment after brain injury", *Brain Injury*, 17(5)

Deb, et.al. (1999), "Rate of Psychiatric Illness 1 Year after Traumatic Brain Injury", *The American Journal of Psychiatry*, 156 (3)

DePompei, R., et.al. (2001), "Traumatic Brain Injury Collaborative Planning Group: A Protocol for Community Intervention", *Journal of Head Trauma Rehabilitation*, June

Feeney, et.al. (2001), "Community Supports for Individuals with Challenging Behavior after Brain Injury: An Analysis of the New York State Behavioral Resource Project", *Journal of Head Trauma Rehabilitation*, 16(1).

Gan, C., Schuller, R. (2002), "Family system outcome following acquired brain injury: clinical and research perspectives", *Brain Injury*, 16(4)

Glenn, et.al. (2001), "Depression amongst outpatients with traumatic brain injury", *Brain Injury*, 15(9)

Gollaher, K., et.al. (1998), "Prediction of employment outcome one to three years following traumatic brain injury (TBI)", *Brain Injury*, 12(4) 255-263

GTA Rehab Network and Toronto ABI Network, (2002), "Results of the ABI/MS Pilot Project"
<http://www.abinetwork.ca/downloads/abims-report-20020930.pdf>

- Holland, D., Shigaki, C. (1998), "Educating families and caretakers of traumatically brain injured patients in the new health care environment: a three phase model and bibliography", *Brain Injury*, 12(12) 993-1009.
- Hoofien, et.al. (2000), "Traumatic brain injury (TBI) 10-20 years later: a comprehensive outcome study of psychiatric symptomatology, cognitive abilities and psychosocial functioning", *Brain Injury*, 15(3)
- Ibrahim, Michel A. et al (2001). "Population-Based Health Principles in Medical and Public Health Practice" *Journal of Public Health Management Practice*, 7 (3), 75-81
- Johnson, S. (2003), "The Importance of a Comprehensive Brain Injury Program", *Brain Treatment*, March/April
- Katz, D., et.al. (2004), "Recovery of Ambulation After Traumatic Brain Injury", *Archives of Physical and Medical Rehabilitation*, 85, June
- Kowalske, K., et.al. (2000), "Vocational Reentry Following TBI: An Enablement Model", *Journal of Head Trauma Rehabilitation*, 15(4) 989-999
- Kreutzer, et.al. (2001), "The prevalence and symptom rates of depression after traumatic brain injury: comprehensive examination", *Brain Injury*, 15(7)
- Kreutzer, J., et.al. (2001), "Charges and lengths of stay for acute and inpatient rehabilitation treatment of traumatic brain injury 1990-1996", *Brain Injury*, 15(9) 763-774
- Langlois, et.al. (2003), "Traumatic Brain Injury-Related Hospital Discharges: Results from a 14-State Surveillance System, 1997", *Center for Disease Control website*
www.cdc.gov/mmwr/preview/mmwrhtml/ss5304a1.htm printed November 2004
- Lannoo, E. et.al. (2004), "Epidemiology of acquired brain injury (ABI) in adults: prevalence of long-term disabilities and resulting needs for ongoing care in the region of Flanders, Belgium", *Brain Injury*, 18(2)
- Leith, K., et.al. (2004), "Exploring the service needs and experiences of persons with TBI and their families: the South Carolina experience", *Brain Injury*, 18(12) 1191-1208
- Martin, E., et.al. (2003), "Telephonic Nursing in Traumatic Brain Injury: A study shows the effect of psychiatric nurses", *American Journal of Nursing*, 103 (10)
- Muus, K. (2003), "Epidemiology of Traumatic Brain Injury", *presentation at the Brain Injury Conference*
- Northeast Regional Acquired Brain Injury Steering Committee (1997), "Northeastern Ontario Acquired Brain Injury Needs Assessment", *East & West Muskoka/Parry Sound District Health Councils*
- Ontario Brain Injury Association (2002) "Caregiver Information & Support Link" <http://www.obia.on.ca>
- Ontario Ministry of Health and Long-Term Care (2002), "Making It Happen: Summary Report of Community Mental Health Services and Supports"
http://www.health.gov.on.ca/english/providers/pub/mhitf/central_east_pen/summary_report.pdf
- Ontario Neurotrauma Foundation (2002), "An Analysis and Dissemination of Current Neurotrauma Incidence and Casual Data in Ontario"
- Ontario Neurotrauma Foundation (1999), "Proposal for an Ontario Brain and Spinal Injury Registry"

- Pace, et.al (1999), “Characteristics and outcomes of a home and community-based neurorehabilitation programme”, *Brain Injury*, 13(7).
- Pickett, et.al. (2001), “A population-based study of potential brain injuries requiring emergency care”, *CMAJ*, 165(3)
- Powell, J. et.al. (2002), “Community based rehabilitation after severe traumatic brain injury: a randomised controlled trial”, *Journal of Neurological and Neurosurgical Psychiatry*, 72: 193-202
- Prigatano, G. (1992), “Personality Disturbances Associated with Traumatic Brain Injury”, *Journal of Consulting and Clinical Psychology*, 60(3)
- Salazar, A., et.al. (2000), “Cognitive Rehabilitation for Traumatic Brain Injury: A Randomized Trial”, *Journal of the American Medical Association*, 283(23) 3075-3081
- Schopp, et.al. (2001), “Gender Differences in Cognitive and Emotional Adjustment to Traumatic Brain Injury”, *Journal of Clinical Psychology*, 8(3)
- Sherk, Carolyn and Consultants, (1994) “A Continuum of Opportunity for People in Ontario with ABI”
- Sherk, Carolyn and Consultants (1999) “Provincial Review of Services for Children and Youth Living with the Effects of an ABI”
- Silver, et.al. (2001), “The association between head injuries and psychiatric disorders: findings from the New Haven NIMH Epidemiologic Catchment Area Study”, *Brain Injury*, 15(11)
- Smart Risk (1998), “The Economic Burden of Unintentional Injury in Canada”,
<http://www.smartrisk.ca/ListingContributions.aspx?sd=77&dd=3>
- Smart Risk (1999), “The Economic Burden of Unintentional Injury in Ontario”,
<http://www.smartrisk.ca/ListingContributions.aspx?sd=77&dd=3>
- Sohlberg, M., et.al. (2001), “What Does It Take to Collaborate with Families Affected by Brain Injury? A Preliminary Model”, *Journal of Head Trauma Rehabilitation*, 16(5) 498-511
- Statistics Canada (1987), “Health and Activity Limitation Survey (HALS)”
<http://www.statcan.ca:8081/english/clf/query.html?&rf=0&qt=hals&charset=iso-8859-1&qm=0&col=pands&oq=>
- Stuart, M. (2004), “Fighting the Silent Epidemic: The Florida Brain and Spinal Cord Injury Program”, *Journal of Head Trauma Rehabilitation*, 19(4) 329-340
- Toronto District Health Council (2000): “Multi-Year Plan 2000;-2003, LTC Populations” Chapter 11.
- Timonen, M., et.al. (2002), “The association of preceding traumatic brain injury with mental disorders, alcoholism and criminality: the Northern Finland 1966 Birth Cohort Study,” *Psychiatric Research*, 113
- Toronto ABI Network, (2003) “Pilot and Implementation of Outcome Measurement in the Toronto ABI Network, Development of a Comprehensive Best Practice Brain Injury Model Phase III”,
<http://www.abinetwork.ca/downloads/abims-report-20020930.pdf>
- Toronto District Health Council (2002), “Toronto Local Health System Monitoring Report”, *Toronto District Health Council*

Toronto District Health Council (2004), "Toronto Small Health Planning Areas: A Population-Based Approach To Constructing New Health Planning Areas in the City", Toronto District Health Council.

Toronto District Health Council (2004), "Toronto Health System Framework", Toronto District Health Council.

Warden, D., et.al. (2000), "A Home Program of Rehabilitation for Moderately Severed Traumatic Brain Injury Patients", *Journal of Head Trauma Rehabilitation*, 15(5), 1092-1102

Waterloo Wellington Dufferin DHC, "ABI Model Development: A Proposed Model of Post-Acute Services for Persons with an ABI and their Families in Waterloo Region and Wellington Dufferin Counties", 2004

Waterloo Wellington Dufferin DHC, "A Study of the Service and Support Needs of Adults with ABI Living in Waterloo Region, Wellington & Dufferin", 2002.

Ylvisaker, M., et.al. (2002), "Perspectives on Rehabilitation of Individuals with Cognitive Impairment After Brain Injury: Rationale for Reconsideration of Theoretical Paradigms", *Journal of Head Trauma Rehabilitation*, 17(3) 191-209