Children and Youth with Brain Injury:

A Review of Rehabilitation Services

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CHILDREN AND YOUTH WITH BRAIN INJURY: A REVIEW OF REHABILITATION SERVICES

Brain injury in children and youth, whether acquired or traumatic, is a significant health and rehabilitation issue within the Province of Ontario. In this document, the incidence and impact of brain injury in children and youth is presented. The effectiveness of rehabilitation interventions for children and youth with brain injury is then reviewed and an overview of services in Ontario and other jurisdictions is provided. *CanChild* Centre for Childhood Disability Research has prepared this document for the Integrated Services for Children Division of the Ontario Ministry of Health and Long Term Care.

INCIDENCE AND IMPACT OF BRAIN INJURY

Incidence of brain injury has been estimated at 250 per 100,000 in the United States (Centres for Disease Control and Prevention, 1998). Approximately 90% of brain injuries occurring in children and adolescents are the result of a traumatic injury (Sherk Consulting Group, 1999). In 1999-2000, the incident rate of *traumatic* brain injury in Ontario was approximately 100 per 100,000 males between birth and 19 years of age, while the rate for females in the same age category was approximately 50 per 100,000 (Walker et al., 2001). These incident rates have decreased significantly since 1993, with the most significant decreases occurring between the years 1993 and 1996 (Walker et al., 2001). Graphs detailing these incident rates are available on the Ontario Neurotrauma Foundation website. It has been estimated that 25% of traumatic brain injuries result in a level of severity requiring rehabilitation services (Carney et al., 1999).

The statistics in the previous paragraph report the incidence of brain injury (i.e., new occurrences in a given time period), not the prevalence (i.e., all individuals with brain injury in a certain population) (CanChild, 2001). These incident rates under-represent the extent of problems related to brain injury in the general population because a brain injury can cause long-term effects. In addition, there have been concerns that children and youth with brain injury may be misidentified. *CanChild* is currently completing a study of children and youth with brain injury and has found that at least 10% of patients entering a children's hospital with a mild brain injury have received a primary diagnosis of fracture, not brain injury.

Prognosis after brain injury ranges from complete recovery to severe disability. There is evidence that the severity and the mechanism of the injury (e.g., trauma, infection, or near drowning) are associated with the child's functional outcome (Klonoff et al., 1993; Max et al., 1999; Ruijs et al., 1993). It has been hypothesized that pre-existing factors such as the child's behaviour and cognitive skills, and the family's status and function may affect the child's

outcome following brain injury (Barry & Clark, 1991; Donders, 1992; Max et al., 1998). However, there is not agreement in the scientific community on the extent to which these premorbid variables influence a child's recovery.

Carney at al. (1999) reviewed 61 studies of needs and prognosis after brain injury. Many of these studies had significant methodological difficulties, which limits confidence in their findings. However, there is indication from this review that children with moderate to severe brain injuries experience multiple difficulties in function in the areas of self-care, mobility, cognition, behaviour, and speech and language. Even children and youth who are assessed to have very mild brain injury with full recovery have been found to have subtle deficits that affect cognition, behaviour and learning. Considering the breadth of issues that may result from a brain injury, a wide range of rehabilitation services is necessary to meet the needs of children who have brain injuries. Individuals who provide these services must take into account issues related to the child's neurological impairment, as well as the fact that children are still developing and changing post injury due to the natural course of human development.

Effectiveness of Rehabilitation Services for Children and Youth with Brain Injury

CanChild researchers examined and conducted systematic reviews of research related to the effectiveness of interventions for children and youth with brain injury and their families. Overall, the systematic reviews of the literature in this area reveal that the number of studies and the methodological quality of research is limited. However, preliminary findings and directions for future research can be identified from these reviews.

One set of systematic reviews was commissioned by the Agency for Health Care Policy and Research (ACHPR) (Carney et al., 1999). Carney et al. (1999) reviewed studies focused on the effectiveness of early rehabilitation, use of special education, and effectiveness of providing support services to families. This review found *no comparative studies evaluating the effectiveness of early intensive rehabilitation* in an acute care hospital for children and youth with brain injury. Research in this area is strongly indicated. The research related to *special education* suggests that between 9 and 38 percent of children with brain injury are referred for special education services, but there was not enough information to judge whether these numbers represented an appropriate level of referrals. Research evaluating the *provision of support services to families* indicates that there is a relationship between social support being available for families and outcomes of family functioning (Rivara et al., 1996). Studies have also found that there is a significant relationship between the severity of the brain injury and stress, which may affect family functioning (Wade et al., 1995; Rivara et al., 1992). The literature related to the family support suggests that services for children and youth with brain injury should include programs to support the entire family, in addition to programs for the child.

CanChild has also critically reviewed the research in several areas of service provision for children and youth with brain injury. The topics selected for the review were identified by service providers and parents of children with brain injury, and include the following:

- Alternative and Complementary Therapies: Controversies

- Alternative and Complementary Therapies: Evaluating the Evidence
- Botulinum Toxin for Children with Muscle Stiffness
- Casts, Orthoses and Splints for the Lower Extremity
- Casts, Orthoses and Splints for the Upper Extremity
- Feeding Assessment and Interventions
- Hyperbaric Oxygen Therapy

"Keeping Current" reports were written for each of the seven topics. The Keeping Currents present a critical review of the most up-to-date research information on each topic. Draft copies of the Keeping Currents are appended to this document. *CanChild* will also be distributing them to Children's Rehabilitation Centres across Ontario, and to others on our mailing list, which includes managers, policy makers, and organizations such as Community Care Access Centres and the Insurance Bureau of Canada.

Similar to the systematic review commissioned by AHCPR (1999), *CanChild* found few studies that focussed on children and youth with brain injury. This is significant because the topics explored by both groups were selected based on consultation with key stakeholders in the area of rehabilitation for children and youth with brain injury. As little research is available that is specific to brain injury, service providers and families must rely on research conducted with children who have other diagnoses that are also neurological in nature (such as cerebral palsy), on research conducted with adults, or proceed with interventions that have not been evaluated. There is clearly a need for well designed, longitudinal research studies investigating recovery, intervention, and transition into the community of children and youth with brain injury.

Research is currently being conducted that addresses this need. *CanChild* is carrying out a longitudinal study of children and youth with brain injury examining their transition from hospital to home and school. This study is funded by the Ontario Neurotrauma Foundation and will take place over the next two years. *CanChild* has also submitted a proposal to investigate the use of Cognitive Orientation to Daily Occupational Performance (CO-OP) with children who have a brain injury. CO-OP is a cognitive intervention that focuses on a child's functional abilities. It has been found to be effective when used with children who have Developmental Coordination Disorder (Polatajko, Mandich, Miller & Macnab, 2001) and the concepts show promise for children and youth with brain injury.

SERVICES FOR CHILDREN AND YOUTH WITH BRAIN INJURY

This section outlines information about the services that are currently available for children and youth with brain injury in Ontario. This information was collected by contacting key informants at children's treatment centres in Ontario (OACRS), the Ontario Brain Injury Association (OBIA), and the Pediatric Sub-committee of the Provincial Acquired Brain Injury Advisory Committee (PABIAC). A number of these informants identified a report titled "*Provincial Review of Services for Children and Youth Living with the Effects of an Acquired Brain Injury: November 1999*", which proved to be very comprehensive and informative. An overview of this report will be presented, followed by a discussion of the current nature of services in Ontario.

Overview of the 1999 Report on Services in Ontario

In 1998, the Ontario Ministry of Health and Long Term Care provided funding to the Pediatric Sub-committee of PABIAC to review the services available for children and youth with brain injury. This review focused on identifying services that were available across Ontario, the strengths of the services, and the areas in which the services could be improved. The results of this inclusive review have been published in a provincial report and a series of regional reports, which provide specific information about the services in particular areas of Ontario. These reports have been made available to the Ontario Ministry of Health and Long Term Care.

The services that were available across Ontario are outlined in Appendix D of the report (Sherk Consulting Group, 1999). Generally, services for children and youth with brain injury were provided by publicly funded hospitals, Children's Treatment Centres and Community Care Access Centres. Some children may also have had access to privately funded services. Of the publicly funded services, only two programs had funding that was designated for children and youth with brain injury and both of these programs were located in southern Ontario.

The Sherk Consulting Group (1999) identified the gaps and major issues with services for children and youth through consultations with families and service providers across the province. The gaps and issues were grouped into six categories: 1) a need for greater awareness and understanding of Acquired Brain Injury (ABI) in children and youth; 2) availability and access to specialized services; 3) shortages of specific types of services and expertise; 4) service coordination and continuity of care; 5) funding issues; and 6) need for data collection, research and education.

Based on the gaps and issues identified through the consultations, the Pediatric Sub-Committee of PABIAC outlined strategic directions and recommendations in four main areas (Sherk Consulting Group, 1999). These areas are: 1) develop a comprehensive and integrated system of services for children and youth with ABI and their families; 2) improve the services and supports provided by the education system to children and youth with ABI; 3) reduce the occurrence and severity of preventable acquired brain injuries; and 4) amend legislation governing private insurance funding for children and youth injured in motor vehicle accidents.

Current Services in Ontario

Telephone consultations with key informants at OACRS centres suggest that the available services, gaps and issues are similar to those identified in the 1999 report by Sherk Consulting Group. In many areas of the province, there continues to be a lack of awareness of brain injury and a lack of specialized services for children and youth who have had a brain injury, particularly for behavioural and mental health issues. As a result, rehabilitation services continue to be provided by service providers who may not have the knowledge or training to best serve this group of children and youth. Some areas of the province continue to report extreme shortages of personnel wherein organizations have not been able to fill vacant positions. Further, issues related to coordination of care remain because the "team" providing services is often comprised of service providers who work for different organizations. *CanChild* research has

found this to be a significant issue because families are generally less satisfied and have poorer perceptions of services when they are provided by a number of organizations (Law, et al., 2001).

However, there have been significant changes since 1999 in a few regions of Ontario that received *dedicated annualized funding* for children and youth with brain injury. These regions include part of the South West Region, part of the South East Region, and Toronto. In Toronto, the annualized funding has enabled Bloorview MacMillan Centre's Neuro-Rehabilitation Program to develop services to meet the long-term rehabilitation needs of children and youth with brain injury in the Greater Toronto Area. The multi-disciplinary team provides traditional outpatient rehabilitation, outreach services (including consultations with staff at the child's school and other therapists), and community resource development (non-case specific educational sessions). This component of the Neuro-Rehabilitation Program has been operating for less than one year and has already received over 130 referrals. The report by the Sherk Consulting Group (1999) details other services provided by the Neuro-Rehabilitation Program.

In the South West Region, the Pediatric Acquired Brain Injury Community Outreach Program (PABICOP), which had been operating as a pilot project, received annualized funding. This program is a partnership between Thames Valley Children's Centre, the Children's Hospital of Western Ontario and five District Health Councils. The PABICOP model addresses issues identified by the Sherk Consulting Group (1999) in that the team focuses on increasing general and specific knowledge about brain injury through educational activities, and consultation with families, schools and therapists who do not have expertise in brain injury. The PABICOP model facilitates coordination of services and promotes effective use of resources (e.g., some consultations are conducted over the phone or by fax). The PABICOP team provides active service to approximately 250 children in 5 of the 9 counties in the South East Region.

In South Eastern Ontario, the Child Development Centre (CDC) in Kingston received annualized funding for an acquired brain injury program. With this funding, the CDC ABI team has been able to strengthen the services they provide to children and youth with brain injury. However, the team's proposal to provide outreach services to children and youth throughout the region has not been realized because the centre only received one third of the anticipated funding. This is an issue because children and youth who do not live close to Kingston are not able to access the same level of specialized ABI services as children who live in Kingston.

Generally, the CDC ABI team has seen an increase in referrals over the past year, even though the incident rate of brain injury is decreasing. This growth has been attributed in part to the education initiatives the team has undertaken over the past year. More children with mild injuries are being referred and there is increased consistency in immediate referral of children with moderate injuries. Better identification of children for rehabilitation services is an example of the positive impact specialized ABI teams can have in a community. This example also highlights the importance of continuing to review the needs of regions across Ontario to ensure that programs are able to meet the changing demands of the population. The South Eastern Acquired Brain Injury Network, along with the Sherk Consulting Group, is currently conducting a Needs Study in the South Eastern Region. This group plans to release the findings of the study to the Ontario Ministry of Health and Long Term Care by summer 2002.

Services in Other Jurisdictions

A basic Internet search was conducted to find information about services for children and youth in jurisdictions outside Ontario. From this search, there does not appear to be any initiatives in other areas of Canada that are significantly different from what is happening in Ontario. However, many resources identified in this search related to individuals of all ages with brain injury. It may be that further exploration of these resources would uncover specific initiatives for children and youth. The following section summarizes two resources that were judged to be relevant to this report.

Brain injury associations are found in most Canadian provinces. These associations are important resources for all individuals who are interested in information and issues related to brain injury including people who have a brain injury, their families, researchers, and policy makers. Although the missions and mandates of these associations vary, each association appears to be involved in raising awareness of and providing information about brain injury.

The British Columbia Ministry of Health Services and Ministry of Health Planning released a report in January 2002 titled *"Guidelines for planning brain injury services and supports in British Columbia"*. This report identifies issues related to providing equitable, coordinated services for individuals with brain injury across the province of British Columbia. The goal of the Ministries is "to strengthen and improve brain injury services and supports in British Columbia" (Ministry of Health Services and Ministry of Health Planning, 2002, p.4). Specific strategies are outlined for all Ministries of the British Columbia government and nearly twenty organizations at the provincial or regional level. This collaborative approach demonstrates a commitment to address the breadth of issues related to brain injury. These guidelines may help to inform the planning of services for individuals with brain injury in other provinces.

CONCLUSION

Despite decreasing incident rates since 1993, brain injury remains a significant issue affecting the health and well-being of Ontario's children and youth, and their families. Research indicates that brain injury can affect all areas of an individual's life and that the functional difficulties resulting from the brain injury can be life-long. Even injuries that are assessed to be *mild* often cause complex difficulties that may not be apparent until several years after the injury.

To address these issues, children and youth who have a brain injury often require and receive rehabilitation services. In Ontario, rehabilitation services are provided by a number of organizations. Issues and gaps in service across the province have been detailed in a report written by the Sherk Consulting Group (1999). Since the time of the Sherk Consulting Group report, dedicated annualized funding has been provided to three organizations in Southern Ontario. This funding has enabled the organizations to develop or enhance the services for children and youth in their area. Specific evaluation of these programs is not yet available, however, anecdotal reports indicate positive successes. Each of the programs has been able to provide services to a greater number of children and families, and referrals have remained constant or have been increasing. In addition, each of the programs has assumed a consultative

and educational role in their communities. This has facilitated an increased awareness of brain injury, enhanced provision of services and enabled a more consistent identification of children and youth requiring rehabilitation services. Long-term evaluation of these programs is important and will develop knowledge regarding models of service delivery for children and youth with brain injury.

As was outlined in this report, there is a lack of research that has evaluated the effectiveness of rehabilitation interventions for children and youth with brain injury. This makes it difficult for families and service providers to make decisions about the services that a child or youth should receive. Similarly, it is difficult for policy makers to develop an overall strategy for providing services and supports to the general population. Longitudinal research investigating the effectiveness of specific interventions with a large group of children is indicated to support the development of best practices, leading to the best outcomes for children and youth.

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