20 years of Advocacy - A Summary of Reports & Recommendations

by BRAIN INJURY NS

BIANS NEEDS ASSESSMENT 2007

Key Recommendations

1. Develop an integrated Nova Scotia strategy for ABI education and injury prevention.
2. Establish a mechanism for planning and coordinating ABI programming in Nova Scotia.
3. Provide core funding to community-based organizations such as BIANS.
4. Develop a comprehensive and coordinated brain injury program for Nova Scotia.
5. Develop an employability assessment approach for those with ABI that considers employment within the context of each individual's experiences and circumstances, is implemented by a multi-disciplinary team, builds upon existing work and promising practices and includes training in its use for health care professionals.
6. Develop an Acquired Brain Injury Registry.
7. Fund an acquired brain injury resource centre.
8. Develop outreach services across the province.

NS DEPT. OF HEALTH PATS PROJECT ABI Focus Group 2008

Common Themes

Education: In particular, education and training for ABI workers. The experience and expertise required for working effectively with survivors of ABI to avoid doing serious and irreparable harm is learned on-the-job today. As a result many potential service providers for survivors of ABI such as recreational community services, respite care, facilities, other healthcare providers, and transportation services are not prepared to deal with and understand the special needs of survivors of ABI. This leads to exclusion of ABI survivors for accessing these services. Education for funding agencies, other healthcare providers and the general public is required to shift the attitude towards placing a high value on funding and services for survivors of ABI.

Services in the Community: For many of the program elements, services in the community for survivors of ABI are non-existent. This makes the need for adequate transportation services, and transportation and accommodation funding a critical component of every program given that most survivors of ABI who need to access services will need to travel to access the service.

'Person' enabled support: To access most of the programs and services associated with each of the program elements, a consistent 'person' enabled support is required by a survivor of ABI. To a survivor of ABI a person is a required cognitive assistance device, not unlike a wheelchair is a requirement for a spinal cord injury survivor.

Integration of Services: To effectively support survivors of ABI living in the community an integration of services is required. For example, lack of transportation services affects many other program elements such as meaningful day-to-day activities and access to many ongoing supports. Many of the program elements are interconnected and a deficit in one service can create disengagement or inaccessibility of other needed services; ultimately creating increased opportunities for crises and dependency on the health system.

Flexible and Accommodating Funding: Prior to a brain injury the survivor may have been a fully functioning and independent member of the community with family responsibilities. In other cases the process of education may have been interrupted. Flexible and accommodating funding alternatives are needed that do not require the individual or family to be on the brink of financial ruin before being able to access funding.

A REVIEW OF ACQUIRED BRAIN IINJURY TRANSITIONAL REHABILITATION PROGRAMS IN NOVA SCOTIA: Peter's Place and Aiseirigh House, Dr. Rees 2012

Key Paragraph:

The guidelines from the Royal College of Physicians and British Society of Rehabilitation Medicine explicitly state that:

It is impossible to separate the needs for healthcare and social services in the long- term management of the effects of ABI on the injured person and their family; joint planning and provision of services are essential to maintain and extend gains made in rehabilitation.

The aim of long-term services should be to enable and sustain optimal societal participation, with personal choice, and will involve helping the person - and family - to adjust to the new situation. Services will need to be delivered in a whole range of settings and, importantly, will involve adapting and developing a range of specialized professional skills and attitudes to working with this client group. A social/educational model of care is appropriate, and effective services will place great emphasis on collaboration between rehabilitation specialists and people involved in the everyday life of the person with the brain injury (RCP/BSRM, 2003, pg 52).

Recommendations

Interdiscipliary Approach & Ongoing Assessment/Evaluation
Access to an interdisciplinary team of regulated health professionals is necessary for the ongoing assessment, intervention and evaluation of functional abilities. For timely and accurate service rehabilitation needs to be systematically evaluated and updated as goals are reached and change over time.
Need for collaboration with other service providers both private and public
Training & Education Since there is no specific program/diploma available to train service workers in ABI it is up to each organization to enhance the knowledge, skills and abilities of their staff in order to maximize rehabilitation following an ABI. Connecting with other service providers, coordinating workshops/training in-services can enhance everyone's ability to provide care for individuals who have sustained an ABI. There are also a number of web-based sites that provide information (e.g., www.abiebr.com) and a number of nationally and internationally recognized associations and organizations that provide annual training. [1]Building partnerships with academic institutions (e.g., colleges, hospitals, universities) to promote education and training is another options. To ensure that appropriate care is provided, staff need ongoing and continual training.
Discharge enviroment A dilemma at both sites is the lack of viable/realistic discharge environments. When admitted to the programs, a discharge environment needs to be identified so that the goal and objectives of the transitional rehabilitation program are geared to achieving those goals in order to progress from the transitional program into the community. Without an explicit discharge environment identified,

the result is that participants are not discharged and new admission(s) into the programs do not occur.
The challenges of discharge are likely related to a number of factors including limited supportive environments that are able to meet the needs of survivors of ABI, an unrealistic desire of an "ideal" living situation or limited desire to define an acceptable level of risk in the discharge environments, limited support/funding, long wait lists for community housing options, and limited availability of alternative community programs (e.g., Supportive Independent Living programs, day programs, respite care, etc). This barrier cannot be solely addressed at the individual level and needs a coordinated approach at the community, municipal, provincial and federal levels.
Need a clear definition of "Transitional Rehabilitation": Neither program has a clear definition of what they mean by "transitional rehabilitation" and what resident/client characteristics are necessary to achieve transition within a particular length of time. Without clearly defined admission criteria on who would most benefit from a transitional rehabilitation approach with a clear time frame in mind, care tends to be open-ended and never ending. There is no doubt that each program offers an ideal place for ABI participants to live compared with alternatives, but both programs are clear that they are not permanent residences.

There is no definitive answer on how long rehabilitation should continue for; some would argue that it is a lifelong process and others would suggest that active rehabilitation is most successful in the first few years following injury/illness and that as progress slows, the approach becomes one of maintenance of gains made. Services of both types are required if appropriate care to individuals with ABI is to be offered, and rehabilitation outcomes should be targeted based on available evidence of clinical information. Therefore, rehabilitation outcomes may range from clients becoming totally independent to having the community (e.g., family, friend, long-term care setting) trained to assist the client that may be dependent for several activities of his daily living. The main goal for transitional rehabilitation is to facilitate "more instrumental activities of daily life, social integration and, when appropriate, return to work/education. Interventions should focus on enhanced participation, improved quality of life, psychological adjustment and carer stress." (Turner-Stoker, 2001, pg. 10).

Addendum to Putting People First Document 2013 Province of Nova Scotia

"There is a general lack of understanding about acquired brain injury and too few supports for the unique needs of that group. Too often, they are offered supports meant for people with intellectual disabilities or mental health issues, which do not reflect their realities and are a poor fit. In fact, the whole approach, philosophy and goals of programs for people with acquired brain injury in fundamentally different than for those with other types of disability. This must be reflected in how programs are planned, how services are delivered and how care providers are trained and prepared for their roles. Typically, the health care system is highly responsive in treating the patient for the trauma that caused their brain injury, but once the acute phase of treatment is over, sometimes extending through to the beginning of rehabilitation, the individual and their family are largely left to fend for themselves to find the services they need."

ROUNDTABLE ON ABI March 2013 – Hosted By Disabled Persons Commission

- Significant gaps include: a behavioural unit; extended stay facilities; ABI Day Center/Clubhouse, case management for long term monitoring; appropriate housing; financial support; access to vocational programs; transportation.
- Education / awareness- doctors, nurses, LPN, CCA and other key personnel need training about ABI; misconceptions regarding appropriate intervention, supports and services for ABI survivors; essential for persons working with, serving or in a care-giving support role to survivors that they be educated about ABI
- Post-acute follow-up – importance of post-acute follow-up; providing opportunities to relearn skills of daily living; residency requirements may preclude many individuals from accessing services- geography; rehab programs should be available throughout province/ availability
- Lack of assistance to help families understand the problems incurred by an ABI survivor
- Develop an integrated continuum of services and supports

Summary of Issues re: Home and Community Based Programs Acquired Brain Injury Lens March 2014

-Home care services need to be able to focus on cognitive rehabilitation. This includes a range of services that support the individual to develop more independence with ADL's, IADL's including supervision of activities, coaching, cueing, and repetition.

-Need to consider a specific type of service in home care to address needs of individuals with an ABI. Include consideration of a personal support worker as a specific type of service for these individuals.

-Consider that Care Coordinators and Managers with knowledge and skill of ABI and ABI care could be a focused team within Continuing Care.

-Gaps in service for children who are transitioning to 'adult' health care need to be addressed. This includes services that could be provided through continuing care.

Proposal for a Provincial ABI Strategy (DHW 2014)

Areas of Focus

- **Awareness and education**- public; survivors/families; health care professionals
- **Health care** – support in navigating services; services be distinct throughout lifespan; best practices across health care continuum; supports in home and community-based care, as well as acute care; interdisciplinary and coordinated approach to care at all stages; case management for ABI individuals; health equity; rehab across all domains; supports for family/caregivers are evident and accessible; flexible funding arrangements
- **Social supports** – consider what is required to support reintegration from basic to higher levels of functioning/independence; expand community capacities; municipalities (housing, supports, transportation); employment (gaining, maintaining); justice/legal system supports/ awareness

Key Consideration

A **'collective impact'** approach to organizing the project would be an effective way to structure the work to develop the strategy. While we know that collaboration is important in this endeavour, collective impact is distinctly different in that it involves a commitment from a group of actors from different sectors to a common agenda for solving complex social issue. The five conditions for success include:

- A common agenda: shared vision for change which includes a common understanding of the problems and issues and joint agreement on how to action change
- Shared measurement: collecting data and measuring results consistently across participants so that efforts remain aligned and participants can hold each other accountable
- Continuous communication: consistent and open communication needed across the many players to build trust, and assure mutual objectives, and,
- Mutually reinforcing activities among all participants: Participants in the work must be differentiated while still being coordinated through a mutually reinforcing plan of action

Backbone organization (e.g. a Secretariat or task force): collective impact requires a separate organization with staff and specific skills to support the initiative and coordinate participating organizations and agencies