



Ontario Neurotrauma Foundation

Fondation ontarienne de neurotraumatologie

Vision 2020 - ONF's 10 year Strategic Plan

Introduction

The Ontario Neurotrauma Foundation has been successful in advancing its work by using research to inform practice and policy in our efforts to reduce or prevent neurotrauma injuries and to improve the quality of life for those living with a spinal cord or acquired brain injury.

The Foundation has core funding with the Research Unit of the Ministry of Health and Long Term Care with a funding agreement that expires March 31, 2009. The Foundation has set in motion a process to develop a ten year Strategic and Program Plan that would inform the Board and our primary funder, the Provincial Government, on the programs and activities necessary to facilitate improvements in the quality of life for those living with neurotrauma and to prevent this injury in the first place. The following information details this plan, our mandate, program priorities and strategy to move forward.

Vision

Vision 2020: Neurotrauma Research and Innovation in Action: Changing lives, changing attitudes and changing our public systems in making a stronger Ontario for all our citizens.

Mission/Mandate

- **Prevent or reduce the incidence and prevalence of neurotrauma injuries.**
- **Enhance the Quality of Life for those individuals living with an acquired brain injury.**
- **Enhance the quality of life for those individuals living with a spinal cord injury.**

Core Values

Activities and programs of the Foundation will demonstrate the following core values:

Consumer Participation – ONF is committed to meaningful consumer input and participation at every stage in the development and operation of the organization and its activities.

Innovation, Creativity and Excellence – ONF will embrace and encourage innovation, creativity and scientific excellence.

Strategic Partnering and Collaboration – ONF will foster strategic partnerships and collaborative efforts with provincial, national and international organizations and individuals to create an environment of cooperation that enhances the exchange of ideas and information and ensures the effective use of resources to achieve the goals of the organization.

Accountability – ONF is accountable to consumers, funders and stakeholders for the effective and efficient utilization of resources to achieve its goals. ONF is committed to fair, transparent and responsible decision-making practices.

Accessibility – ONF will strive to ensure its activities are accessible to and reflective of, the diverse population of Ontario.

Continuous Learning and Evaluation- As a learning organization ONF will strive to improve its own activities through evaluation, dialogue, and partnership.

ONF Over the Past Five Years: Accomplishments to Date:

Ontario Neurotrauma Foundation was awarded refunding of \$5 million a year for five years in April 2003. The funding supported the new Strategic Plan, **New Directions for Neurotrauma Research in Ontario** with a focus on reducing the incidence and prevalence of neurotrauma injuries and in improving the quality of life for those living with a spinal cord or acquired brain injury.

The key focus of the mandate was, *“to embark on a journey to become a strategic funder. This will be characterized by increased emphasis on relevance, and consumer involvement in identifying research priorities, and the use of granting approaches that target research funding to the priorities established by ONF.”*

ONF has been successful in realizing this mandate and positioning the organization as not only a strategic funder but an organization that has integrated research and knowledge mobilization. Our journey has evolved the organization from a grant funder to a strategic funder and has over time an increased an emphasis on knowledge mobilization. Our success over the past five years has been critical in establishing our capacity to move our new Strategic Agenda forward into the next ten years.

The Foundation has developed within its three program themes (Injury Prevention, Spinal Cord Injury and Acquired Brain Injury) and as a collective, success within knowledge production, knowledge brokerage, knowledge mobilization and capacity building.

Knowledge Production

- ONF has supported 122 major projects within the last five years

| Prevention: 2003 – 2008 | |
|--------------------------------|------------------|
| Operating Grants: | 24 |
| Pilot-Feasibility Studies: | 3 |
| Demonstration Grants: | 8 |
| Other: | 5 |
| Grand Total: | 40 Awards |

Spinal Cord Injury: 2003 – 2008

| | |
|--------------------------|------------------|
| Operating Grants: | 33 |
| Pilot-Feasibility Study: | 5 |
| Demonstration Grants: | 1 |
| Other: | 3 |
| Grand Total: | 42 Awards |

Acquired Brain Injury: 2003 – 2008

| | |
|----------------------------|------------------|
| Operating Grants: | 32 |
| Pilot-Feasibility Studies: | 6 |
| Other: | 2 |
| Grand Total: | 40 Awards |

- Convened three major Evidenced-based review series within the areas of Acquired Brain Injury (ERABI), spinal cord injury (SCIRE) and completed seven series in Injury Prevention Best practices including three implementation guides.
- Convened three expert panels in spinal cord injury with a focus on pressure sores, urological and bowel management. These panels identified current knowledge gaps and future areas of research opportunity.
- Convened one expert panel on youth development and workplace injuries in partnership with the University of North Carolina. Two more symposiums will study this issue further for eventual identification of key policy development themes in both jurisdictions.
- Major symposium of children and youth and ABI to identify gaps and develop a research agenda
- Sample bibliometric indicators suggest ONF researchers have contributed to the academic literature in high impact peer-reviewed journals such as Nature, the New England Journal of Medicine, Canadian Medical Association Journal, Journal of Neurotrauma, Archives of Physical Medicine and Rehabilitation and British Medical Association Journal, and presented at provincial, national and international conferences and symposiums, commanded special editions of journals to present its

Evidenced based reviews (ERABI and SCIRE), thus positioning Ontario as a significant contributor and centre of excellence for this work.

- ONF's success in this area has created opportunities to partner nationally and internationally with the Canadian Institutes of Health Research, Victoria Neurotrauma Initiative (Australia), National Institutes of Health (United States), Quebec's FRSQ-REPAR, University of North Carolina and a variety of other organizations.

Knowledge brokerage

- Facilitated the development of three major communities of practice: Ontario Injury Prevention Managers Alliance in partnership with the Ontario Public Health Association; Ontario SCI Solutions Alliance in partnership with the Canadian Paraplegic Association and the Ontario Alliance for Action on Brain Injury in partnership with the Ontario Brain Injury Association, Toronto ABI Network, Provincial ABI Committee and the Ontario Association of Community-Based Boards for ABI Services.
- Partnered with Reseau provincial de recherche en adaptation-readaptation (FRSQ-REPAR) to develop an Ontario/Quebec rehabilitation research collaboration that involves six teams and over 50 researchers from both provinces.
- Provides infrastructure support to the Ontario Rehabilitation Research Advisory Network (ORRAN)
- Partnered with the Rick Hansen Foundation in the National SCI Translational Research Network and now the National SCI Solutions Network
- Brokering the development of seniors falls initiatives within the Ageing at Home strategy with the LHINs
- Partnering with the Neurological Health Charities Canada in their activity towards a Neuro-Strategy
- Sponsored 30 provincial and national conferences in the areas of spinal cord injury, acquired brain injury and injury prevention.
- Facilitated the development of the link between 20 local brain injury associations and the Ontario Brain Injury Association
- Developed a partnership with the Insurance Bureau of Canada that facilitated both the insurance industry, clinicians, consumers, and other key stakeholders in the development of a process for the identification of brain injury
- Participated and informed the development of the Provincial Injury Prevention Strategy

Knowledge Mobilization

- Developed the ABI Uptake Strategy (ABIKUS) with over forty researchers, clinicians and consumers that support the Evidence Based Review of ABI work. The resulting clinical guidelines are now being implemented and evaluated in two rehabilitation and two community-based settings.
- Supported specific Knowledge Mobilization grants that developed education sessions around an earlier ONF project on Guidelines for

Educators in dealing with children with ABI and developed our earlier work on women and SCI into a specific web site (www.proactivespinalnetwork.com).

- Initiated KM incentive grants to support novel approaches in the mobilization of ONF funded research.
- Manage the knowledge mobilization component of ONF funding activity in partnership with the research team, stakeholders and decision makers.

Capacity Building

- Established an Injury prevention mentorship program that engaged 8 students and mentors
- Funded 74 studentships and fellowships in the areas of injury prevention, spinal cord injury and acquired brain injury.
- Reviewed our earlier activity in this area and determined that 69% of students and fellows funded by ONF remain in Ontario and 61% remained engaged in the area of neurotrauma suggesting the success of this initiative.
- Built researcher capacity within the 6 ONF/FRSQ-REPAR funded teams and funded in partnership with FRSQ-REPAR three neurotrauma summer exchanges
- Successfully engaged consumers in our work through direct sponsorship of some 20 SCI consumers to attend a National SCI conference, engagement of 300 consumers (community of interest) linked to our consumer research newsletter, Neuromatters, and a further 5000 who have received a copy of this newsletter.
- Through facilitating the Ontario Brain Injury Association and 20 community associations to develop formal linkages, capacity was developed that enables the Peer Mentor Support Program to be implemented in these communities across the province.
- Development of communities of practice in all areas of our research interest be it prevention practitioners, or clinical or service delivery professionals.

The Knowledge Mobilization Challenge

The Mission of ONF is to reduce the incidence and prevalence of neurotrauma injuries and to improve the quality of care for those living with a spinal cord or acquired brain injury. While research and the development of new knowledge is an essential activity, it is insufficient in addressing the mission of the Foundation. It is insufficient because we know that the development of new knowledge does not in of itself translate into outcomes.

The translation of research results to clinical practice outcomes is known to be slow and if occurring hap hazard in nature. Information from Graham et al in their article, Lost in Knowledge Translation: Time for a Map? Notes that researchers in the United States and the Netherlands estimate that 30-45% of patients do not receive care according to scientific evidence and that 20-25% of the care provided is not needed or is potentially harmful.(19) Graham goes on to

suggest “For many reasons, research findings are not being taken up in practice settings, and many patients are not receiving the best possible care. This situation results in inefficient use of limited health care resources”.(20)

To improve this situation, the Foundation has created an integrated Research and Knowledge Mobilization Framework to guide its funding activities. The development of an “implementation science” model as a further articulation of this framework is a key determinant in meeting the mission of the Foundation and creating the value for the government and ultimately our consumers. Knowledge mobilization is not an activity or set of discourses at the end of a research project, but integrated and deliberate process at the very outset of the development of a research activity.

This integration continues as the new knowledge is either sought or created and then put into action through a process that includes engagement of stakeholders and partners, identification of barriers to adoption, a focus on implementation science, monitoring adoption, as well as outcomes and a well articulated exit strategy to ensure sustainability of the impact and outcome.

The relevance of our research and knowledge mobilization agenda has been informed and continuously tested against our logic model. The model was developed in partnership with our stakeholders: consumers, researchers, clinicians, policy makers and service providers to identify the necessary outcomes that would define success. Our model recognizes that this is a multi step process through the delineation of immediate, mid term and final outcomes.

The ONF Research and Knowledge Mobilization framework informed by our logic model is at the core of our Strategic Plan and refunding submission. It is our contention that this model will address the current challenges in knowledge mobilization and move research investments to applied action and outcome.

An understanding of the continuum of research and knowledge mobilization activities is central to our development of a solution agenda towards a research question. Where each activity is on this continuum varies considerably, depending on the state of the science, the capacity for implementation, the state of readiness for adoption, the relationships between stakeholders, partnership building and the capacity or engagement of researchers and stakeholders around this problem.

Work at the entry point is essential to establish a research and knowledge mobilization plan that accounts for these issues and makes the appropriate and timely investments at the right stage. The project management activity to ensure this occurs is a key element of our investment proposal and our infrastructure costs.

The ONF model (Exhibit A) illustrates our approach to moving research along a continuum from how we engage stakeholders within the research process, defining the questions, conducting research, mobilizing and implementing research results and sustaining the impact and outcomes. Our model is

complemented by a further articulation of our approach to putting knowledge into action (Exhibit B). This model has been developed by the thoughtful work undertaken by Graham, I. et al.

These two frameworks work together to describe how the Foundation develops its research and knowledge mobilization activity within the three program areas of Injury Prevention, Acquired Brain Injury and Spinal Cord Injury.

The Research Framework is described in detail in the Appendix. The Knowledge to Action Framework describes a deliberate process and set of activities that will move knowledge into action. This is key to understanding the effort and resources required to be successful in impacting and sustaining outcomes.

ONF holds the ongoing evaluation of its integrated program of research, as critical to the success of its Vision 2020 Strategy. It views evaluation frameworks as guideposts to addressing the key objectives of accountability, hand-off and sustainability, and steering/management. To the extent that the value of a project predicated on the perceived risk associated with its level of funding, its completion, and its sustainability, ONF's project support role focuses on buying down the risk. This approach demands choosing evaluation frameworks that can be used as a guide to achieve the stated objectives.

ONF is a funding supporter of the Canadian Academy of Health Sciences (CAHS) initiative to identify evaluation frameworks that address five key elements: objectives – accountability, steering, resource allocation, advocacy for sustainability; measures – outputs, outcomes, impacts in the scientific, social, cultural, and economic domains; levels of aggregation – low (researcher), medium (the ONF program), high (the discipline of neurotrauma); timing – longitudinal or cross-sectional; and methods – eight frameworks have been considered. Choices within each of these elements influence choices of other elements.

The publication of the full CAHS report is anticipated in the first quarter of 2009. ONF will refine the details of individual projects based on project-by-project framed by the hierarchical considerations.

ONF Model Integrated Research - Knowledge Mobilization

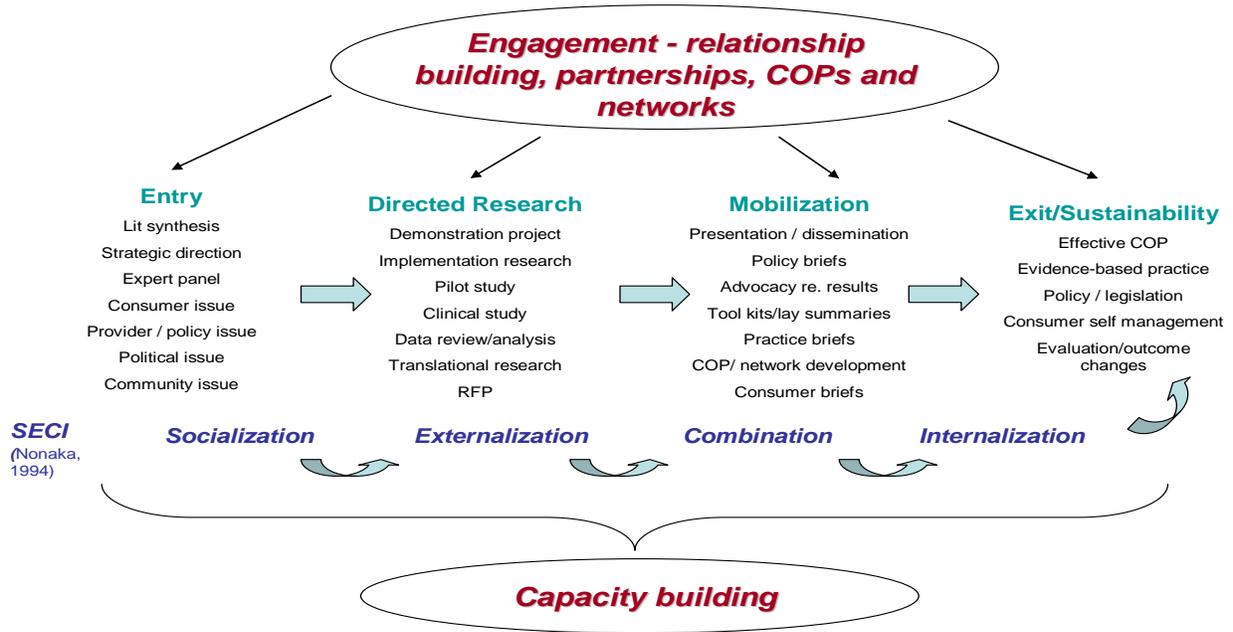
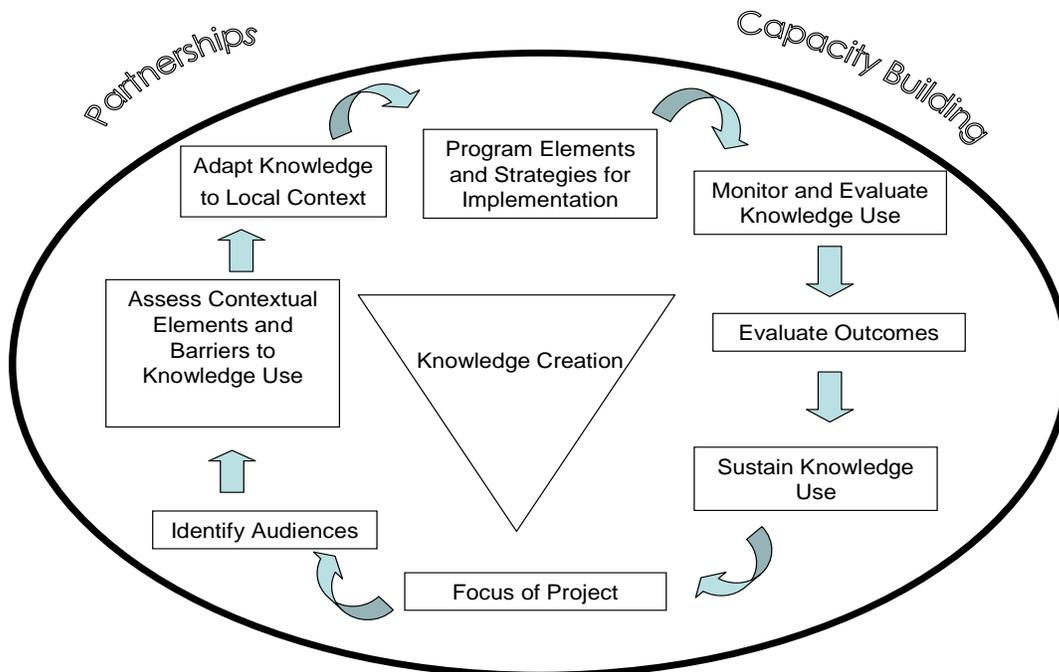


Exhibit A

ONF Approach – Knowledge to Action



Based on a model developed by Graham et al, 2006

Program Plans

PREVENTION STRATEGIC VISION FOR 2020

Introduction

NEUROTRAUMA INJURY PREVENTION VISION FOR 2020

The Ontario Neurotrauma Foundation envisions an Ontario where the incidence and impact of spinal cord and head injuries can be reduced by 20% by year 2020 to ensure safer Ontario communities, playgrounds, roads, workplaces and schools.

The impact of neurotrauma in Ontario communities is significant, predictable and preventable. Every two hours in Ontario, one person is hospitalized with a traumatic head injury and every year 300 people are hospitalized with a spinal cord injury. In 1999, there were over 4,000 deaths and 570,000 injuries in Ontario with a total cost of more than \$5.7 billion with unintentional injuries accounting for \$4.5 billion of the total cost (SMARTRISK, 2006). Falls were the most costly unintentional injury, totalling more than \$1.9 billion with the majority of these costs being attributed to seniors' falls. Motor vehicle collisions were the second most costly unintentional injury at more than \$1.1 billion. Significant regional variations in the incidence, severity, and economic burden of injury were also detected, notably in the North where there is the highest death rate, hospitalization rate, permanent disability rate, and per capita economic burden (SMARTRISK, 2006).

In the case of neurotrauma injuries, the personal and financial costs often last for a lifetime and not only affect the injured person but his or her family too. Head and spinal cord injuries are severe chronic conditions with long term health complications (i.e. pressure sores, spasticity, cognitive impairments, increased risk of re-injury), psychosocial adjustments (i.e. depression, isolation, etc), school integration and performance (i.e. learning difficulties) and community integration implications (i.e. specialized housing, transportation, employment, etc.). Prevention research, policies and interventions are the only reasonable investment to prevent these injuries from occurring in the first place.

Injuries are determined by multiple causes which involve the interplay of various components such as the environment, the individual and his or her personal characteristics, the sociocultural context and interpersonal relationships (Volpe, 2004). The challenge is to determine how these variables interact with each other, their weighted relevance in specific situations and how prevention efforts can be maximized for best possible results.

For these reasons, population-based injury prevention programs and activities need to be directed at raising awareness of potential injury risks, building skills to face such risks, building healthy public policies and systems to protect citizens from these risks and changing the man-made environment for safer communities. Neurotrauma injury prevention requires a comprehensive,

multisectoral approach that draws on a broad knowledge base, coordinated efforts with partners, and evidence-informed best practices interventions. Prevention also demands a shift in thinking towards a culture of safety across the lifespan and spheres of life (see Appendix 1).

We live in a society where more children and young people die from injury than all other causes of death combined, where falls in older adults may be the deciding factor between independent and dependent living, where inflicted infant head traumas occur as a result of a lack of parental support, where people living with neurotrauma injuries are at greater risks of getting re-injured and where injuries are considered as an act of fate that cannot be avoided. Neurotrauma injuries are catastrophic not only because of their human and financial consequences but also because they are still not part of the citizens' awareness and our health system infrastructures. Neurotrauma injuries are a broad public health problem which requires the involvement of many sectors and the public itself. To do so, people need to be aware of risks and conditions leading to injuries and be equipped to respond in a preventative manner when need be.

ONF's Role

ONF's ultimate goal is to reduce the incidence and prevalence of head and spinal cord injuries while raising awareness for an improved culture of safety in every day life. All Ontarians can potentially be at risk for an injury of this magnitude depending on their age, activity level, exposure to risky environments, substances and medication, skill levels, judgment in assessing risks, pre-disposing factors and key social determinants of health such as poverty, housing, and employment. A population based approach to neurotrauma injury prevention is necessary to leverage efforts, outreach and resources. A major roadblock to successful implementation of best practices and uptake of neurotrauma injury prevention messages and practices is the lack of awareness of these injuries being preventable and predictable. A societal shift in mindset is required and key stakeholders need to act in a coordinated manner with supports in place (research, surveillance, legislation) to make a difference.

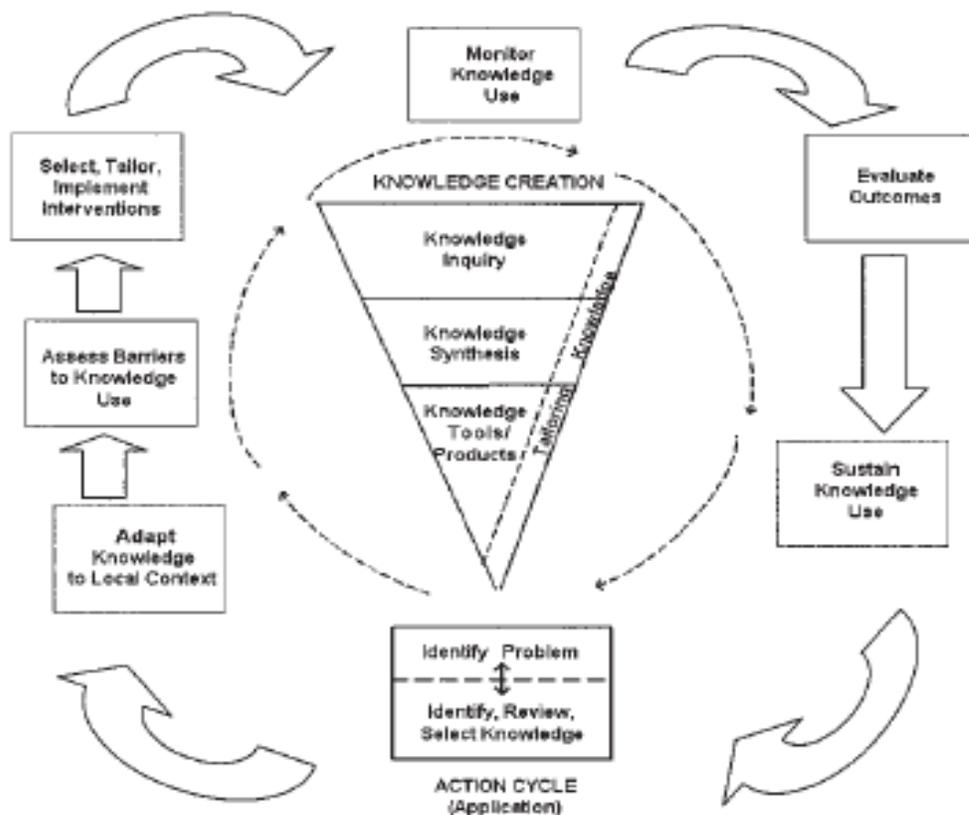
ONF's prevention initiatives focus on head and spinal cord injuries that occur throughout the life course. Understanding the relationship between risk and protective factors and knowing the best ways to prevent these injuries, is crucial to effective decision-making, policy and program development. ONF's role is to ensure that research is translated into action while improving or maintaining the quality of life of all citizens. ONF provides evidence which can inform legislative changes, bring best practices into action and mobilize partners on evidence-based interventions.

ONF's approach to neurotrauma injury prevention is based on an integrated model where research (or knowledge) informs policy and changes practice through knowledge mobilization and sustainability. However, ONF's approach is as good as the systems in which it evolves, the partnerships that can be formed (see Appendix 2), the availability and accessibility of data, and the capacity of

health practitioners, their organizations and communities to implement evidence-informed injury prevention interventions.

ONF brings knowledge into action by working with partners in identifying the problem that needs addressing, generating or reviewing the research relevant to the problem, adapting the identified knowledge to the Ontario context, select, tailor and implement evidence based interventions, monitor and evaluate knowledge use and ensure that successful interventions are sustained and brought to scale across the province (see Figure 1 below).

Figure 1



Graham, ID, Logan J, Harrison MB, Straus SE, Tetroe J, Caswell W & Robinson N. Lost in Knowledge Translation: Time for a Map? *The Journal of Continuing Education in the Health Professions*, Volume 26, pp. 13–24.

ONF’s Neurotrauma Prevention Priorities

The current body of knowledge identifies several leading causes of head and spinal cord injuries: falls, across the lifespan; road safety/driving; workplace injuries; sports injuries; shaken baby syndrome; re-injury; and risk taking behaviours. These areas are ONF’s research, knowledge mobilization, partnership building and best practice implementation priorities from now until the year 2020.

Some of these neurotrauma injury prevention areas have a broad base of knowledge (e.g. seniors' falls prevention, road safety, shaken baby syndrome) whereas other areas (e.g. re-injury, youth and risk-taking) require more research and support across disciplines. In all cases, coordination of efforts, collaboration and partnerships are required to move our current knowledge forward, generate new knowledge and implement evidence informed practices into action.

Falls across the lifespan

- Falls can happen at any age and can cause severe injuries. Risk factors are different depending on the age, setting, events, and medical status. An example is provided (see Appendix 3) of ONF's approach in bringing research into action which focuses on seniors' falls prevention.
- Partnerships: LHINs, public health units, sports and recreation, health professionals, housing

Road safety/driving

- Traffic and driving injuries affect everyone, from children to seniors. Research topics of interest range from pedestrian safety, driver and passenger safety, driving behaviours and distractions, to recreational use of other motorized vehicles.
- Partnerships: CanDRIVE, Ministry of Transportation, public health units, Centre for Addiction and Mental Health, urban planners, municipal governments

Workplace injuries

- ONF aims to reduce neurotrauma injuries in the workplace in partnership with key organizations involved in promoting occupational and health safety (e.g. some current partners are the Construction Safety Association of Ontario, Ontario Safety Association for Community and Health Care, the United Steelworkers).
- Partnerships: Ministry of Labour, WSIB, United Steelworkers, University of North Carolina, Institute for Health and Work, Ontario Safety Association in Community and Healthcare

Sports injuries

- Traumatic brain and spinal cord injuries occurring in sports are often a result of severe blows, falls, impact and shock. ONF aims to prevent and reduce sport injuries in general and in hockey in particular.
- Partnerships: CSRO, hockey world, media, other sport associations, Ministry of Health Promotion

Shaken baby syndrome (Inflicted Infant Head Trauma)

- If a baby is shaken with force, it can lead to immediate brain injuries with a lifetime of effects. ONF aims to prevent and reduce the incidence of Inflicted Infant Head Trauma by working with partners involved in providing information, education and training to parents and caregivers.
- Partnerships: Best Start Resource Centre, Safe Kids Canada, hospitals, public health units, community organizations, health professionals

Re-injury

- Previous head and spinal cord injuries along with other co-morbid factors can lead to subsequent injuries. The issue of re-injury is under explored and ONF is committed to develop this area of neurotrauma prevention research.
- Partnerships: Dale Brain Injury Centre, Toronto Rehabilitation Institute, others to be determined

Risk taking

- Risk behaviour is one of the many factors leading to neurotrauma. Speculation can be made on the precursors of risk behaviours such as co-morbid factors, peer pressure or other environmental issues. An increased body of knowledge is needed on this issue along with the design of best practice neurotrauma injury prevention interventions.

ONF's Neurotrauma Injury Prevention Directions

Guided by the commitment that 20% of head and spinal cord injuries will be prevented by the year 2020 in Ontario, we work to not only support outstanding research excellence but more importantly to move our research into policy and practice and to sustain the impact of change for improved outcomes. In the field of neurotrauma injury prevention, this approach requires great efforts, time, commitment and investment for sustainable results.

Overall Prevention Program Goals:

- To move neurotrauma injury prevention research into action
- To promote a positive culture of safety
- To reduce health care service utilization and costs
- To promote the well being of Ontarians by preventing neurotrauma injuries

To advance towards these goals, ONF identifies key interrelated objectives with associated actions for each (some of these objectives and actions are inspired by the New Zealand Injury Prevention Strategy, www.nzips.govt.nz).

Objectives:

- Raise awareness and commitment to neurotrauma injury prevention

- Advance neurotrauma injury prevention information and knowledge
- Integrate neurotrauma injury prevention activity through collaboration, coordination and partnership
- Develop and support the implementation of evidence informed injury prevention interventions
- Strengthen neurotrauma injury prevention capacity and capability
- Strengthen the policy development framework supporting neurotrauma injury prevention

ONF'S OBJECTIVES AND ACTIONS

Objective 1: *Raise awareness, leadership and commitment to neurotrauma injury prevention*

Actions:

- Support stakeholders and partners in their awareness raising injury prevention initiatives (e.g. conferences, meetings, social marketing campaigns, etc.)
- Encourage provincial, regional and local government to demonstrate leadership in neurotrauma injury prevention
- Raise commitment and motivation for improved neurotrauma prevention among all stakeholders across sectors, including vulnerable groups
- Customize and disseminate research results and interventions pertaining to neurotrauma prevention to various stakeholders in partnership with key agencies such as SMARTRISK, Public Health Injury Prevention Managers
- Provide leadership by seeking partnerships and agreeing to partnerships that are likely to bring best practices into action across the province
- Support organizations, agencies, government and other stakeholders who have responsibilities and mandates focusing on neurotrauma injury prevention priorities (i.e. Public Health Injury Prevention Managers, LHINs, Ministry of Health Promotion, Ontario Agency for Health Protection and Promotion, NGOs, etc.)
- Provide leadership in bringing together various sectors and disciplines on key injury prevention strategies (e.g. safe hockey)

Anticipated outcomes for 2020:

- Ontario citizens have an increased understanding of neurotrauma injuries and how to prevent them
- Targeted common timely messaging on neurotrauma injury prevention issues across the province
- Coordinated awareness raising injury prevention initiatives among stakeholders and partners
- Current leadership is strengthened and new leadership emerges to support neurotrauma injury prevention strategies and activities (i.e. new researchers)
- A positive culture of safety is emerging at the population level

Objective 2: *Advance neurotrauma injury prevention information and knowledge*

Actions:

Research

- Create a targeted research agenda in neurotrauma injury prevention based on the needs of policy decision makers, partners, citizens and other key stakeholders who can put research results to use (e.g. public health, LHINs, etc.)
- Create a targeted research agenda based on current knowledge gaps around neurotrauma prevention (e.g. re-injury, risk taking, etc.)
- Create a targeted neurotrauma prevention research agenda that draws on multiple disciplines and sectors (e.g. risk taking and the fields of psychology, sociology, etc.)
- Review the literature and identify evidence informed best practices in neurotrauma injury prevention
- Provide communities and partners with up to date best practices with accompanying guides for implementation
- Identify stakeholders and potential partners interested in moving promising and best practices into action
- Support partners by providing expertise, evaluation and evidence on neurotrauma injury prevention interventions of interest
- Ensure that neurotrauma injury prevention research strategies focus on key injury issues, particularly those where effective interventions are not well established
- Connect with other jurisdictions and create research teams for neurotrauma injury prevention

Surveillance

- Work with and connect policy decision makers, researchers, epidemiologists and end users of surveillance data (i.e. Ontario Agency for Health Protection and Promotion)
- Support and influence policy decision makers in building a centralized neurotrauma injury surveillance system
- Improve access to existing data systems and sources
- Analyze and interpret neurotrauma injury surveillance data for use by health professionals and other injury prevention stakeholders (with partners such as SMARTRISK and the Ontario Agency).
- Enable communities to access and analyze local data in order to identify and prioritize local injury issues

Anticipated outcomes for 2020:

- Better understanding of how neurotrauma injuries happen and can be prevented
- New neurotrauma prevention knowledge is identified and generated; new evidence informed interventions are identified and implemented, and effective interventions are brought to scale across the province.

- An increased access to surveillance data and systems informs the provincial, regional and local planning activities of government, non-profit organizations, businesses and community groups and agencies.
- Gaps in knowledge are identified and research agendas are developed to investigate these gaps.
- Knowledge exchange activities among partners, across sectors and disciplines have increased with a broader base for neurotrauma injury prevention expertise.
- Stakeholders and partners increase their use of evidence in building their injury prevention program to reflect existing best practices.
- Decision makers know who to contact for latest neurotrauma prevention knowledge, how to use this information for policy development and where gaps in the system still remain.
- All citizens have access to culturally appropriate neurotrauma injury prevention messages that make a difference.

Objective 3: *Integrate neurotrauma injury prevention activity through collaboration, coordination and partnership*

Actions:

- Ensure collaborative relationships for neurotrauma prevention within and between provincial, regional and municipal government agencies, non-government organizations, community sectors and businesses
- Establish, strengthened, or support coordination mechanisms (e.g. Public Health Injury Prevention Managers Alliance) to ensure injury prevention activity is integrated and best practices are implemented
- Maintain current partnership and seek new partners interested in implementing and sustaining neurotrauma injury prevention best practices (i.e. Ontario Agency for Health Protection and Promotion)
- Reach out to partners across disciplines and sectors to expand the breath of neurotrauma injury prevention policies, programs and initiatives
- Seize opportunities for partnerships based on provincial, regional and local initiatives (e.g. Aging at Home Strategy with the LHINs)
- Injury prevention messaging, knowledge and interventions are integrated in primary health care services (e.g. family health teams, private practice, etc.)

Anticipated outcomes for 2020:

- Fragmentation and duplication of efforts are reduced across sectors and disciplines
- The injury prevention sectors and systems work in a seamless manner and can mobilize the field when needed
- A broader base of health professionals is promoting a culture of safety with the appropriate messages and interventions for each segment of the population and sectors.
- Policies, programs and interventions are informed by various disciplines and sectors and therefore, are more comprehensive in nature

Objective 4: *Develop and support the implementation of evidence informed neurotrauma injury prevention interventions*

Actions:

- Support key stakeholders such as public health units and LHINs in implementing neurotrauma injury prevention best practices
- Augment the number of best practices interventions implemented across sectors and disciplines in Ontario
- Provide consultation services and expertise to interested partners on identifying best practices, designing evidence informed programming, implementing and evaluating best practices interventions
- Bring knowledge, expertise and resources across sectors and disciplines for a broader approach to neurotrauma prevention policies and interventions
- Articulate lessons and implementation guidelines from various best practice pilot projects for uptake across the province
- Support the implementation of evidence informed injury prevention interventions for vulnerable groups (e.g. Aboriginal Peoples, etc.)
- Ensure that interventions are designed to engage those groups who are most of risk of injury, or cause the most injury to others.

Anticipated outcomes for 2020:

- An increased number of best practice interventions for neurotrauma prevention are implemented across the province
- Best practice interventions for vulnerable groups are identified and implemented to reduce health inequities.
- The incidence and prevalence of neurotrauma injuries are documented and reduced by 20%
- The infrastructure that addresses injury prevention strategies and activities is improved and contributes to the reduction of duplication and better use of limited resources
- Less demand is being placed on the health care system due to neurotrauma injury
- Less disruption and increased productivity for businesses and service organizations.

Objective 5: *Strengthen neurotrauma injury prevention capacity and capability*

Actions:

- Increase understanding of how neurotrauma injuries happen and how the key contributing factors can be eliminated or controlled
- Promote the development of personal and professional skills in neurotrauma injury prevention through partnerships with the education sector, workplaces, public campaigns, partners' promotional activities, and evidence-informed interventions.

- Increase the capacity and capability of public health injury prevention managers to collectively plan, coordinate, implement and evaluate best practice interventions
- Support injury prevention researchers and multi-disciplinary research teams to focus on key neurotrauma injury issues
- Build the capacity of the Ontario research community to undertake neurotrauma prevention research (e.g. internships, mentorships)

Anticipated outcomes for 2020:

- Increased professional capacity of injury prevention stakeholders (e.g. public health units, LHINs, etc) to implement best practices
- Improved organizational infrastructure and ownership to support the implementation of neurotrauma prevention best practices
- Expanded pool of researchers devoting their career to neurotrauma injury prevention research and evaluation and expanding the knowledge base in neurotrauma injury prevention
- A recognized neurotrauma injury prevention infrastructure and system

Objective 6: *Strengthen the policy development framework supporting neurotrauma injury prevention*

Actions:

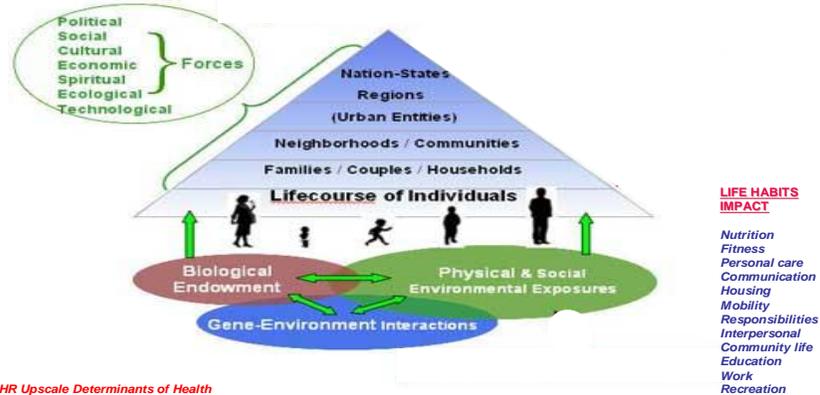
- Increase our understanding of the information needs of policy decision makers and the policy development processes
- Conduct regular international scans in identified priority areas to update the evidence base on effective policies, regulations, and programs (e.g. New Zealand Injury Prevention Strategy, etc.)
- Conduct domestic policy reviews to identify opportunities for the different levels of government to take action to reduce injury in their respective jurisdictions based on best evidence
- Provide expert information and analysis and facilitate the introduction of evidence-based policies, regulations, and programs to reduce the risk of neurotrauma injury in work, home, school, roads and recreation environments
- Help shape an Ontario Injury Prevention Strategy that pervades across sectors, is evidence informed, integrated, comprehensive and makes a difference

Anticipated outcomes for 2020:

- Policy makers are aware and use evidence informed neurotrauma injury prevention knowledge to support their decision making process
- Stakeholders mobilize, take ownership and support the Ontario Injury Prevention Strategy and focus on its inter-sectoral implementation
- Resources are injected to support the revised Ontario Injury Prevention Strategy

APPENDIX 1

THE LIFECOURSE APPROACH TO NEUROTRAUMA PREVENTION



| <i>Early Childhood</i> | <i>Youth</i> | <i>Adulthood</i> | <i>Seniors</i> |
|------------------------|--------------|------------------|----------------|
| Shaken Baby Syndrome | | | |
| Playground injuries | Sports | Sports | |
| Falls | Falls | Falls | Falls |
| Road safety | Road safety | Road Safety | Road Safety |
| | Workplace | Workplace | |
| Risk taking | Risk taking | Risk taking | Risk taking |
| Re-injury | Re-injury | Re-injury | Re-injury |
| Environment | Environment | Environment | Environment |

APPENDIX 2

Key Injury Prevention Strategies, Activities and Partners

Neurotrauma injuries are a public health and a multi-sectoral issue that include stakeholders in various fields. Through a life course perspective, the injury prevention research stream addresses issues associated with complex system change, and the impact of social determinants on health. In order to achieve the goals of the Injury Prevention program, ONF works with numerous partners to identify key areas where we can influence the systems that focus on preventing neurotrauma injuries and promoting health. The field of injury prevention is shaped by its stakeholders, policies, strategies, programs, research and systems. ONF is cognizant of all these elements and operates with the intent to support current provincial strategies and build on these collective efforts such as:

- The [Ottawa Charter for Health Promotion](http://www.who.int/hpr/NPH/docs/ottawa_charter_hp.pdf) is a guiding framework for action in injury prevention as it recognizes the need for comprehensive strategies and systemic action (http://www.who.int/hpr/NPH/docs/ottawa_charter_hp.pdf).
- The [Ontario Injury Prevention Strategy](http://www.mhp.gov.on.ca/english/injury_prevention/strategy.pdf) was launched in 2007 by the Ontario Ministry of Health Promotion to reduce the frequency, severity and impact of preventable injuries (http://www.mhp.gov.on.ca/english/injury_prevention/strategy.pdf). The Ontario Injury Prevention Strategy certainly provides an understanding and framework as to how all stakeholders could work together to achieve better outcomes in reducing injuries however, the Strategy is not well known by all ministries and sectors. Some work still remains to be done to create an interministerial awareness and interest in the Strategy and rally all ministries, with partners from the public and private sectors, for shared leadership and investment. On the positive side, the Ontario Injury Prevention Strategy has contributed in bringing together key stakeholders from the non-profit sector with public health managers and practitioners to discuss joint initiatives in injury prevention. Alliances and partnerships have been formed and joint initiatives have been developed and implemented. ONF is pleased to have been part of this process and to have facilitated some of the alliances and partnerships.
- The Ministry of Health and Long Term Care has developed the [Ontario Chronic Disease Prevention and Management System](http://www.toronto.ca/health/resources/tcpc/pdf/conference_lee.pdf) to provide a common policy framework to guide efforts toward effective prevention and management of chronic diseases. This framework is likely to shape how chronic conditions such as brain and spinal cord injuries are addressed in the health system (http://www.toronto.ca/health/resources/tcpc/pdf/conference_lee.pdf)

- The [Ontario Public Health Standards](#) specify those programs and services that all boards of health are required to provide. Specific standards on injury prevention are described and represent the mandate of all public health units (<http://wesurvey.wemanageyour.com/healthunit/pdf/FINAL%20Draft%20OPHS%20for%20Consultation.pdf>).
- The [Ontario Agency for Health Protection and Promotion](#) is a potential new partner for injury prevention. The Agency's mandate is to bring academic, clinical and government experts together to create a centre of public health excellence in the province. The Agency will be a centre for specialized research and knowledge in public health, focusing in the areas of infectious disease, infection control and prevention, health promotion, chronic disease and injury prevention and environmental health. It will provide technical and scientific assistance, rapid on-site field support, as needed, specialized communication and training, as well as standards input and practical tools for implementing best practices.

Spinal Cord Injury Research Strategic Plan for Vision 2020

Currently ~41,000 persons with Spinal Cord Injury (SCI) are living in Canada in community or in institutional settings (www.icord.org). Almost one third of the Canadian SCI population presently live in Ontario and about 300 new injuries are sustained each year in Ontario. Costs to support each person, over their lifetime, range from \$1.25 million to \$25 million (www.canparaplegic.org) depending on the severity of their injury.

Spinal cord injury results in catastrophic anatomical, physiological and psychological impairments and its outcomes intersect with the environment, the community and the ability of an individual to live a productive life in society.

Disability that results from SCI is more than the impact of impairment on an individual; it encompasses the results of the interaction between the impairment, the social, economic and built environment and the opportunity for full citizenship and community participation.

The goal of the ONF Research Strategy is to maximize functional outcome and community integration to enhance the quality of life for individuals with SCI. Thus our research agenda follows a continuum from identification of problem or knowledge gap, oftentimes through systematic reviews of available evidence, knowledge accumulation in areas across the continuum of care, translation and dissemination of knowledge and best practices to appropriate stakeholders and partners. All of this is within the context of customizing research outcomes to partner's needs and creating a readiness to support the cycle of implementing, monitoring evaluating and sustaining of new knowledge. ONF in simplistic words "holds hands and walks the partners through the front door entry to firmly grounded exit strategy, following a systematic step by step mutually developed road map".

ONF guiding principles in setting research priorities and implementing them are driven by consumer needs, by capitalizing on the excellent research capacity within Ontario, by understanding provider and policy maker needs and by leveraging ONF funds with other national and provincial SCI research funds, initiatives and activity. In particular, ONF has established a solid foundational partnership with The Rick Hansen Foundation and the offspring, National SCI Solutions Network

An important element of the ONF Research Agenda is to constantly explore new collaborations to facilitate the delivery of enhanced multidisciplinary healthcare services and other community supports over the life course of persons with spinal cord injuries. These partnerships embrace provincial organizations and institutions, as well as interprovincial and international collaborations, all with the same mandate of knowledge generation and translation to the SCI community, and other similar disability groups. Each initiative involves stringent evaluation for consumer needs and for cost effectiveness i.e. recognizing the huge economic burden of the current health delivery system for individuals with SCI and the need to maximize the usefulness of limited economic resources.

What will be the impact of our research programs by 2020?

We seek to:

- Identify new discoveries to best manage, retain and restore neural function after trauma; these discoveries will embrace novel surgical, pharmaceutical, biotechnological (e.g. stem cell) and other acute care management strategies, improved rehabilitation therapies, and enhanced community supports.
- Reduce the personal and economic impact of secondary medical complications through enhanced prevention, detection and management strategies. This may involve identifying barriers and facilitating access to available supports and services to optimize function and health in home community.
- Enable appropriate and timely access to an integrated continuum of healthcare services, including primary care and health maintenance services, specialty care, medical rehabilitation, long-term care, and health promotion programs.
- Reduce the number of emergency visits, hospitalization and re-hospitalization post injury.
- Increase individual's efficacy to be active managers of their care by engaging in informed participation in health and other supports services needed on a continuous and routine basis.
- Ease transition from youth to adulthood with appropriate supports which presently needs more attention.
- Maximize quality of life by increasing opportunity for education, employment and other productive desired activities.
- Make available more accessible, affordable personal transportation and other assistive technology.

Enabling Platforms:

In order to accomplish our goals we plan to establish or consolidate existing platforms upon which to build our research endeavours. These platforms include:

- Capacity building through a variety of personnel support programs which include recruiting and training the best and brightest students, residents and post doctoral fellows, enabling established scientists committed time to advance the ONF research mandate, facilitating clinical/research exchanges and establishing partnerships.
- An integrated provincial SCI data management strategy developed as a model of health information management for Ontario. The strategy will lay the foundation for receiving and housing web-based data and in a provincial prescribed entity Institute of Clinical Evaluative Sciences (ICES), aligned with Ministry of Health and Long term Care's (MoHLTC) health information management strategy and transformative health services delivery agenda. The data set will create a sustainable

authoritative health informatics resource to be used by various stakeholders to facilitate the understanding of SCI, integrate SCI knowledge, and foster collaboration between decision makers, health care providers, and researchers. The data will be utilized to improve SCI care, the quality of life for persons with SCI and reduce societal costs. The strategy will align seamlessly with Rick Hansen Spinal Cord Injury Registry (RHSCIR) and the SCI Solutions Network to inform the national research agenda from the Ontario lens.

A Provincial Clinical Research Network of scientists and institutions committed to undertaking clinical trials and other forms of research to benefit the SCI community. This network will interface seamlessly with National and International networks with similar mandates.

- Systematic Evidence Synthesis and Review. A structure to enable systematic reviews of existing knowledge (e.g. the SCIRE process) and partnership/collaboration with the Global Mapping Strategy initiative in Melbourne Australia by the Victoria Neurotrauma Initiative.
- A web-based information sharing technology (e.g. telehealth) that will enable ready access to state-of-the-art information for consumers, providers, researchers, and policy makers

SCI research programs to address in vision 2020

1. Medical, Surgical and Therapeutic Advances:
Translational research from late stage animal trials to early stage clinical application; proof of principle studies for innovations in care; novel imaging and other technologies designed to improve the provision of care across the continuum from acute injury, rehabilitation to community integration
2. Management of Secondary Medical Complications:
Specific targeted research to address the consumer identified priorities for improved prevention, detection, and management of medical complications arising from SCI e.g.: pressure sores, pain, urinary and bowel incontinence, ventilator dependence and mental health. Many of these complications must be considered within the context of a complex chronic condition.
3. Health Services, Access and Delivery:
 - Research designed to improved access to primary care and coordination among providers.
 - Research and implementation strategies, such as building communities of practice, to establish effective self management practices for chronic disease states affecting the individual with SCI

- Transitions from young to adulthood
- Women's Health

4. Full citizenship

Disability Supports e.g. Specialized Transportation; Assistive Technology and enhanced employment opportunities

ONF research framework is woven in partnerships

What partnerships means to ONF?

ONF Partnership is a collaboration among two or more entities or organizations to achieve clearly identified goals. Thus partnerships are embedded in our research activities right from beginning to end. For our partnership to have a strong foundation and future strategy, we have identified that engagement of stakeholders is fundamental for the envisioned outcomes. **Engagement** is an active process of involving our partners and stakeholders into our research activity, which impacts us, them, as well others outside the group.

Consumers/persons with spinal cord injuries are active participants in the design and evaluation of our Research Program. Along side it, stakeholders and other service providers are held responsible and accountable for integrating the seamless, continuous delivery of resources and services by being informed by our research and knowledge translation process. Thus our partnerships enhance creativity, performance, implementation, evaluation and sustainability of our research agenda.

There are limited resources, wider gaps and growing needs for services to assist persons with disabilities. To find local solutions to local challenges it is necessary to establish collaboration among various organizations to achieve clearly, mutually identified goals to provide efficient services within the community. Partnerships among health care and social service policy makers, providers and service delivery personnel, along with individuals needing care, must be built and maintained constantly. This eventually leads to a co-ordinated use of resources, shared responsibility, mutual benefits and multi-stakeholder collaboration that will ultimately remove barriers that isolate and fragment the process of service delivery. Further it will lead to healthier community life by increasing creativity, efficiency, effectiveness and by finding a "workable new solutions" and a "stronger common voice". A prime example of this form of partnership is through the creation and sustenance of the Ontario SCI Solutions Alliance.

In summary, community of practice, capacity building by partnership, is an ongoing process for ONF, which continues to develop and sustain resources within the community. It also engages our partners and shares a common vision to fulfill needs of all, especially individuals with disabilities who require special care and attention.

ONF partners

- Rick Hansen National SCI Solutions Network

- Rick Hansen Foundation
- Canadian Paraplegic Association
- Ontario SCI Solutions Network
- Local Health Integration Networks
- Rehabilitation Institutions and Hospitals
- Ontario Universities
- Community SCI service providers
- Family Health Teams
- Center of Effective Practice
- Réseau provincial de recherche en adaptation-readaptation (FRSQ-REPAR)
- Ontario Rehabilitation Research Advisory Network (ORRAN)
- Victoria Neurotrauma Initiative
- Ontario Health Technologies Association (OHTA)
- Public-Private Partnerships e.g. insurance industry
- Cross Ministry Partnership within Ontario government
- Service Providers Partnerships
- Health care Professionals Partnership
- National organizations e.g. Neuroscience Canada and Canadian Institutes of Health Research (CIHR)

SCI Research Programs

Medical, Surgical and Therapeutic Advances

Goal: To improve the quality of care, along the continuum from acute injury, rehabilitation to community integration, through the discovery and implementation of innovations in medical, surgical, pharmaceutical and therapeutic strategies. These strategies will be designed to provide Neuro-Restoration/Neuro-Protection, Neuro-Recovery and functional Neuro-Rehabilitation while mitigating the risks of medical and other health complications.

Objectives:

- To build on the existing leadership of Ontario-based scientists in the translation of stem cell technologies to early stage human clinical trials
- Support the conduct of a proof of principal studies introducing innovations to the treatment and management of individuals with SCI throughout the continuum of care.
- Enable evaluation of innovative health delivery demonstration models e.g. SCI Pilot
- To facilitate the conduct of clinical trials of investigator driven or industry sponsored studies of pharmacological or biotechnological advances, through the infrastructure of a clinical trials network
- Support for clinical trials network in Ontario.
- Support the “best and brightest” – funding for graduate students, post doctoral fellows, young faculty and established researchers.

- Support for promising pre-clinical basic science research to facilitate translation into clinical trials.
- Support for Phase I and II clinical trials and partner between NGO's and academic institutions/industry would greatly facilitate this initiative.

Secondary Medical Complications

Goals: Target research to address the consumer identified priorities for improved prevention, detection, and management of medical complications arising from SCI e.g. pressure sores, pain, urinary and bowel incontinence, ventilator dependence and mental health issues such as depression and suicide and to facilitate the implementation of best practices. Two illustrative areas are neuropathic pain and pressure sores.

Neuropathic Pain

Goals: Improve quality of life by adequate management of pain by using evidence based management protocols and strategies.

Objectives:

- To increase awareness that neuropathic pain is a separate entity and should be managed as such and not as any general pain.
- Promote new models of service delivery for neuropathic pain.
- Increase evidence-based knowledge and to enhance current treatment protocols.
- To use a multi-prong approach to pain management such as pharmacological, surgical and alternate therapies like behaviour modification, acupuncture, massage etc.
- Take late stage animal research models to early clinical trials to enhance current treatments available.

Action:

- To support late stage animal research to early Phase 1 Human Trials.
- Consistent protocols to diagnose and treat pain.
- Use evidence based best practices for pain.
- Multidisciplinary approach management strategy.

Outcomes:

- Early identification, diagnosis and management of pain.
- Have an evidence-based strategy to address chronic pain as a health service, economic and ethical issue.
- Improve quality of life and decrease pain and suffering.

Pressure Sores

Goal: To reduce incidence and prevalence of pressure sores and develop a capacity to use the best available management protocols.

Objectives:

- To develop protocols to deliver best evidence based approach to prevent and treat pressure sores.
- Early detection and treatment to reduce hospitalization, pain and suffering along with productivity.
- Develop and sustain capacity to deliver best practices for pressure sore management.

Action:

- Develop a data management platform and system for delivering evidence based novel approaches for prevention and treatment of pressure sores.
- Train and retain health care professionals to adopt, deliver and evaluate best management protocols.

Outcomes:

- Reduce incidence and prevalence of pressure sores.
- Reduce the cost of expensive and prolonged treatment by using new and better treatment protocols.
- Increase productivity and ability to pursue desired activities.

Primary care & Self Management

Goal 1: To maintain function, health and prevent medical complications and to reduce co-morbidities by having access to primary care services and co-ordination of care.

Objectives

- To develop capacity by having more family health teams prepared to serve individuals with spinal cord injury.
- To develop the best suitable and sustainable model of primary care service delivery for persons with a physical disability.
- Evidence-based research to support family physicians to have a built in remuneration system to take individuals with more complex health care needs and be the lead point for co-ordination of their care.
- Academically increase disease specific knowledge to ease the anxiety, fear and dilemma among health care providers to manage SCI.
- Make primary care available in each community depending on its specific needs and available supporting infrastructure.

- Increase our current pilot projects to more communities and translate this as a continuous sustainable program.
- Increase and maintain collaboration amongst primary care, specialist care and access to other necessary goods and services.
- Health care systems ability to have a “one stop” healthcare delivery system of care.

Actions

- To increase awareness of the role of health prevention and promotion for persons with spinal cord injury.
- To engage with local health care communities to find their needs and to support and provide primary care within their settings.
- Share with our partners and stakeholders the findings from the pilot projects and how to implement them as a continuous program.
- Bring health professionals together from each pilot site to partner and share their programs and activities with each other.
- Engage with the academic family practice program developers to increase SCI related education in the curriculum to increase family physicians knowledge of SCI and its management.
- Share our results and knowledge with policy developers to support primary care and primary care health teams to provide services to spinal cord injury population.
- Assist in developing expert team based specialist support to family health teams to manage complex health issues of SCI consumers.
- To raise awareness among policy makers that providing healthcare needs to be supported by various ministries and coordinated with other goods and services.
- Evaluate the family health team approach to provide primary care to persons with SCI in specific and to all persons with physical disability at large and make appropriate recommendations.

Outcomes

- Identification of the primary care needs of different communities and suitable paradigm to develop, support and provide primary care.
- Have appropriate funding allocated to family physicians and family health teams to serve complex care needs clients.
- Increase knowledge of the primary care teams, to decrease anxiety and increase efficacy to serve SCI consumers.
- Pooling of resources and expertise to develop and share success factors and find solutions to existing and foreseen barriers.
- Development of communities of practice.
- Decrease emergency visits for common ailments and acute medical crisis.
- Reduce hospitalizations and re-hospitalization due to the most common and frequent medical complications such as a pressure sore, bladder infection or a respiratory infection.
- Increase global health and wellness and decrease overall morbidity and mortality.

Goal 2: Building Communities of Practice to Deliver Chronic Disease Self Management Program (CDSMP) in Ontario.

To increase self efficacy of individuals with a spinal cord injury in specific and individuals with disability in larger framework to take responsibility to manage their life post injury. The major goal of the CDM model is to create a productive interaction environment where informed, activated patients engage with prepared, proactive health care and other service provision practice teams in the interests of optimal clinical and functional outcomes

What are Communities of Practice and Chronic Disease Self Management Program?

The approach ONF will take to increase the delivery and support for the chronic disease self management program is by building community of practice (CoP). CoP is a group of people who come together to do something better and who share the same vision. Community of practice is an ongoing phenomenon that develops and sustains resources within the community as well catalyses the process of making a commitment from partners and stakeholders to share with themselves and others. This sharing of knowledge will also prime and accelerate the implementation and delivery process for the CDSMP. CoP will also engage its partners, especially individuals with disabilities who require special care, attention and empowerment.

The Chronic Disorders Management model (CDSMP) is a planning framework for managing chronic health disorders and attendant disability. *CDSMP* was developed by a team of researchers from Stanford University and is being delivered for common chronic conditions like Asthma, Diabetes, Hypertension and Heart Diseases for more than two decades.

CDSMP is based on the concept of empowering individuals by increasing their efficacy to take charge and responsibility to manage their health conditions. This process involves the systematic provision of education, to increase individual's skills and confidence in managing their health and life habits through the life course in the face of disability through regular assessment, goal setting, and problem-solving support. Self-management support takes the form of validated evidence-based behaviour change, by developing a personalized, collaborative action plan with specific behavioural goals and tactics for overcoming the barriers to achieve individual goals. Individual's involvement in managing their care is referred to as "self management", which has been described as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition". For self management to be effective, it needs to encompass the "ability to monitor one's condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life". This definition implies that self management is more than simple adherence to treatment guidelines; it incorporates the psychological and social

management of living with a chronic disease. However, chronic diseases vary in the extent to which they intrude on psychological and social worlds, and consequently in what might be necessary for effective self management.

Objectives:

- To make individuals with SCI take responsibility to manage their health and life activities.
- To have peer leaders capacity, to deliver the program within their communities.
- Use innovative techniques and technology to deliver programs in remote communities with a small SCI population.
- To decrease medical complications and emergency visits.
- Decrease economic burden of care.
- To have healthcare professionals and institutions support and be part of the program.

Actions:

- To partner with healthcare professionals, consumers and Local Health Integration Networks (LHINS) to deliver the program within their communities.
- To evaluate the program and share the results with others delivering the program.
- Find local resources to deliver and support the program.
- To build capacity by assisting in training more leaders to deliver the program.
- Videoconference the program in remote communities.

Outcome:

- Consumers will be prepared to actively partner with their health care team in all aspects of care and decision making.
- Consumers taking responsibility to manage their health condition.
- Have champions such as physicians and other health care providers to recommend and support the chronic disease self management program for SCI consumers.
- CoP will result in pooling of resources, shared responsibility, mutual benefits and multi-stakeholder collaboration as well as a large scale program implementation.
- Extension of delivering the program to individuals with other physical disabilities.
- Cost savings by decreasing medical complications, hospital visits and admissions.
- ONF to become experts in advising and supporting other jurisdictions and provinces to deliver the program.

Health Services, Access and Delivery

Women's Health

Goal: To have a better understanding and delivery of health care services specifically specialized and targeted to women with spinal cord injuries.

Objective:

- To promote and deliver preventive services.
- To have access to specialists with knowledge and expertise to deliver sexual and reproductive health services.
- Develop capacity to increase current limited technology to support reproductive and obstetrical needs of women with SCI.
- Support women's choices to have children and enjoy family life.

Action:

- Promote research that will improve and support the need of preventive health, such as mammograms and pap smears as part of primary care.
- Increase knowledge and expertise of health care workers to support mothers with SCI during pregnancy and childbirth.
- Support and promote research to develop assistive technology and childcare equipment for SCI injured parents to care for their children.
- Develop a health care professional team, based on an approach to manage care of mothers with SCI, during pregnancy and delivery.

Anticipated Outcomes:

More women with a SCI will be able to get preventive care. Also more women will be able to conceive and raise children and enjoy motherhood. There will be more availability of cost effective childcare equipment by using universal design.

Transition from youth to adulthood

Goal: Development of a collaborative sustainable strategy to promote and provide a paradigm of a service delivery process during transition from youth to adulthood.

Objectives:

- To increase independence, smooth transitions within the continuum of care and services, increased goal attainment, empowerment, and satisfaction of persons with SCI as well their families from youth to adulthood transition.
- To reduce stress of children, families, and service providers.

- Reduce duplication and gaps in planning and provision of services.
- A well developed service delivery plan which meets individualized needs.

Actions:

- A partnership and collaboration between various service providers and ministries funding programs for children such as Health, Education and Community and Social Services.
- Develop and deliver services that focus on self-determination, empowerment, decision making, choices and control for youth and families.
- Develop and evaluate community capacity-building programs that focus on developing assets within the community and individualized funding programs for families provide families with choice and control for finding services and supports for the young adult.

Outcome:

- Better understanding and support to provide important information to policy makers regarding how the process of transition works and supports needing to serve individuals and families during transition.
- More individuals will be able to pursue intended educational and other life goals and objectives

Full citizenship

Transportation

Goal: Have access to accessible and affordable personal transportation that supports the full integration of consumers into the community and their full participation as active and productive members of the society.

Objective:

- Increase the availability of personal vehicles, by decreasing the current cost of the vehicle, driving aids, insurance and maintenance.
- Making specialized driver training available in more cities in Ontario.
- To increase the understanding of economic benefit to all partners and stakeholders on having low cost vehicles and its long term outcomes.
- To decrease the burden on the public transportation system and increase its efficiency.
- Increase individual's ability to attain education, employment and pursue other daily activities as any peer without disability.

Action:

- To bring together and build a partnership between automakers, Transport Canada, Insurance Bureau of Canada, private insurance companies, health care professionals (occupational therapists doing assessments and driver training) and other relevant stakeholders.
- Augment the number of driving assessment and training sites.
- Conduct cost analysis.
- Evaluation of consumer's outcomes on self defined indicators of quality of life.

Outcomes:

- More individuals and families will be able to own personal vehicles.
- Number of individuals dependent on the public transportation system will decrease.
- More vehicles will be manufactured and sold which will support automaker industry and economy.
- More business to insurance companies by increase in consumer capacity to buy and insure vehicles.
- Fewer burdens on family and formal caregivers by increasing SCI consumer's ability to drive themselves or use modified vehicles easily.
- Evidence based support to impact stakeholders such as Insurance Bureau of Canada, Ministry of Transportation and automakers.
- Individual's ability to engage in more outdoor activities, education, employment and recreation and more desired pursuits.

Employment

Goal: To identify the determinants of labour force participation, and the impact of lost earnings, and recovery of employment for individuals with SCI.

Objectives:

- To identify the facilitators and barriers to gainful long term continuous employment.
- To identify and develop appropriate supports and policy to increase the employment rate post injury.
- Increase the understanding about availability of transition services to promote movement from educational settings and post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, and community-based services for participation in the labour force.
- Make parity in employment for individuals with a spinal cord injury.
- Increasing the availability of validated theories, measures, and methods to improve measurement, data sources and estimates, and enhance identification, evaluation and prediction of the factors that facilitate

successful labour force participation and work-related transitions across the life span.

Actions:

- Identify and develop methods and practices to integrate unique needs of employers and the SCI population, to improve employment outcomes across the life span.
- To work with employers addressing concerns about costs of accommodations and generate innovative approaches to alleviate obstacles to accommodations.
- To support research that will help in understanding determinants of employment such as economics, legal issues, healthcare, functional status, and attitudes that drive employer practices in regard to employment of persons with SCI and other physical disabilities.
- To conduct longitudinal studies of cost benefits not only as a financial entity but its impact on global health, function and quality of life of an individual.

Outcomes:

- Strengthen the scientific basis of disability-related employment policy, practice, and research, by providing evidence-based information and analyses that improve the understanding of employment trends.
- Increase the understanding and supports available for individual labour force participation and school-to-work transitions.
- Enhance knowledge of the rapidly changing social and economic environments that affect employment opportunities and outcomes across the life span.
- More individuals with SCI being employed in appropriate qualified jobs. Less economic burden on tax payers to support disability social assistance and other programs.

Health Care Technology

Goal: Make “user friendly assistive technology” available to increase access and maintain function.

Objective:

- Increase awareness and availability of assistive technology and demystify that it is very specialized, has limited demand, and consequently limited markets with reduced economic rewards for manufacturers.
- Address that universal design and capitalizing on the assumption that many improvements intended for specific SCI population or people with disabilities, serve similar functions and purposes for the larger population.

- Build capacity, knowledge and resources to provide telehealth and telerehabilitation.
- Evidence based support to implement home telehealth and telerehabilitation as an effective alternative to traditional hospital care.
- To increase evidence that telehealth is a method designed to use advanced telecommunication technologies to exchange health information and provide health care services across geographic, time, and other barriers.
- To support innovative technology development and use.
- Prioritize and support government and private initiatives regarding emerging opportunities.

Action:

- Develop partnerships with public and private funders along with government priorities to develop capacity within local communities to make new technologies like diaphragm pacing, for ventilator dependent consumers available and affordable.
- Engage with stakeholders such as Ontario Assistive Device Program and the industry, to share evidence based research knowledge about the economic return on mass production of cost effective assistive devices.
- Develop and implement demonstration projects on Home Tele-health and Tele-rehabilitation.
- Develop telehealth research agenda and making the best use of the results in health care practice by understanding the underlying rationale for how and why the technology is effective and important to advance the scientific rationale of this method of care delivery.

Outcome:

- Increase individuals ability to access needed assistive technology to increase and maintain function.
- Improve health and decrease occurrence and better management of medical complications.
- Better quality of life and community participation by use of technology like pacers instead of ventilators or other invasive respiratory supports.
- Early identification and management of co-morbidities.
- Decrease hospitalization and health care costs.
- Increase opportunity to engage in desired activities like employment, sports and family life.

In Summary

The ultimate thrust of our Research Program is to enhance the quality of life for individuals with SCI. This will be accomplished by better managing their medical and health complication and increasing their participation in life activities and reducing the social, economic and ethical burden on individuals, their family

and society. In many situations disability, poverty, ill health and seclusion are grouped together.

ONF's systematic research has a strong foundation and approach to improve clinical care, functional outcome, and health care policy rectification; which will lead to reduce impact of disability and enhance participation and quality of life for those living with a spinal cord injury.

**Acquired Brain Injury
Strategic Vision for 2020**

The Ontario Neurotrauma Foundation envisions an Ontario where people with Acquired Brain Injuries (ABI) are provided with evidence-informed and

comprehensive treatment and services to improve their participation in the community as full citizens.

ABI is defined as damage to the brain which occurs after birth that may be caused:

- traumatically i.e. from an external force such as a collision, fall, assault or sports injury)
- non-traumatically, through a medical problem or disease process which causes damage to the brain (internal process or pathology such as anoxia, infection or brain tumours). This excludes stroke.

ABI often results in a complex combination of cognitive, psychosocial, behavioural and physical problems. Even people who sustain supposedly mild injuries can struggle to return to pre-injury status.

Close to **500,000** people in Ontario of all ages live with Acquired Brain Injuries (ABI), which amounts to almost 4% of the population of the province.

Recent ONF research demonstrates that in 2006, **17,482** people sustained a *traumatic injury* to the brain and had interactions with emergency departments and hospital admission for the injury. This research also shows that **19,311** people in the same year had a diagnosis that involved some sort of medical problem or disease process affecting the brain (*non-traumatic ABI*), which may or may not have resulted in residual damage to the brain. This does not include stroke but does include hemorrhagic vascular incidents that result in complex residual damage to the brain, and are thus ABI. ONF is still working to extract the data on the percentage of the 19,311 people that had residual damage and it is currently presumed to be 40 %.

In addition, building from population-based data, there are **72,962** Ontarians who sustain a mild traumatic injury every year. It is currently unknown what percentage of these visit emergency rooms, but it is known that a large percentage do not and therefore would not even be included in the 17,482 traumatic injuries. Based on internationally accepted numbers, up to 10,944 of these Ontarians every year will not recover as expected and will develop persistent problems due to their injury.

Extrapolated cost data conservatively indicates that ABI is more than a **\$2-billion** issue annually for Ontario, including direct medical costs and indirect costs such as lost productivity.

ABI can occur at any age, from early infancy through to old age, and while ABI begins in the health system from an injury event or illness, it continues through the lifespan of the individual, affecting many areas of their life - economically,

socially, and within the community. As a complex chronic disorder, ONF approaches ABI across the lifespan and the life course.

While prevention efforts are essential, the half a million people who are currently living with the effects of an ABI, plus those significant numbers who sustain an injury on an annual basis, have unique lifelong challenges that require integrated systems to optimize their ability to function and improve their quality of life.

This strategic vision requires a comprehensive, multi-sectoral approach that draws on a broad knowledge base but requires capacity to create new knowledge. It also requires coordinated efforts with partners, evidence-informed approaches and interventions for treatment and care, and environments and capacity to take knowledge and apply it with appropriate implementation that can lead to sustainable change.

The greatest gains that can be made involve developing more consistent approaches to identification of ABI, better understanding the prevalence and impact of ABI, improving system integration and coordination, and working towards more consistent and evidence-informed practice across the province.

Further, this vision cannot be achieved without collaboration with key stakeholders, to gather input and perspectives on ONF activities; to obtain a spirit of 'buy-in', engagement and collaboration from those stakeholders and partners that will be essential in creating knowledge and mobilization activity as well as the receivers of knowledge; through formal partnerships to facilitate implementation, evaluation and effective change; and to plan for careful sustainability and exit strategies for ONF once practice is in place

What will be the impact of our research program by the year 2020?

The overarching impact will be:

Improved quality of life for people with ABI and their families, and increased efficiencies in the systems that treat and support them

Specifically:

- Recognition of ABI as a significant cause of disability, and one that impact all ages
- Better identification and follow-up of ABI, particularly in the school system
- Consistency of identification, treatment, care and services, supported by provincial and regional standards
- Better classification of impact and outcomes and forecasting of appropriate supports
- Comprehensive frameworks, supported by a Provincial ABI Dataset and widespread evidence-informed standards for systems
- Achievement of flexibility, accessibility, regionality and suitability of care in the provision of treatments and services
- More seamless linkages between the rehabilitation setting and the community
- Development of a web of services available for all levels of entry
- Better planning for individuals as they experience life transitions and aging
- Removal or alleviation of system barriers, such as wait lists for services and eligibility for delivery of appropriate supports to enhance function
- Age appropriate approaches to ABI

What do we need to achieve this impact by 2020?

- ABI data and surveillance - to inform on regional and provincial system issues, utilization, transition, and coordination between points of care
- ABI as integrated systems - to enable suitable and seamless care, appropriate utilization and planning on systematic levels to address ABI across the life course
- Longitudinal data - to demonstrate the long-term impact of ABI and facilitate prognostication, and evaluate the efficacy of strategies
- Regional and provincial focus – to enables local focus, cross-regional planning and provincial standards to be adopted
- Capacity - on individual, organization and systemic levels, for researchers and those who are the receptors, users and implementers of the research
- Education and awareness of ABI - for all those working in areas impacted by ABI in public and private spheres and in the community.

The Context of the ONF's ABI Research Programs:

Lifespan and life course approach to ABI

ABI differs from other types of sustained illness or injury in that it occurs across the entire lifespan. ABI as a result of traumatic and non-traumatic causes is increasing in the older population, adding further to complexities of aging. ABI often occurs in children and youth, and can result in lifelong challenges, the extent of which are more clearly seen as the child 'grows into their injury' and struggles during their development and transition to adulthood. Other times it occurs in the prime productive years of life, which can not only affect the long-term health and productivity of the individual with ABI but also the earning potential of family members who must look after them.

ONF tackles the issues of ABI across the lifespan by studying the longer-term impacts of brain injury; by researching approaches to mitigate the effects of injury at various life stages and across points of transition; and developing and assessing tools to forecast needed supports to achieve maximum function.

ABI as a complex chronic disorder

ABI often results in a complex combination of cognitive, psychosocial, behavioural and physical problems. While some individuals are able to compensate for some deficits, and many go on to live full and productive lives, the majority of people with ABI will need to manage the various problems resulting from their injury during their entire life course.

A Complex Chronic Disease is a condition involving multiple morbidities that requires the attention of multiple health care providers or facilities and possibly community (home)-based care. A patient with complex chronic disease presents to the health care system with unique needs, disabilities, or functional limitations. (Department of Veterans Affairs, United States)

People with ABI experience these multiple morbidities (cognitive, psychosocial, behavioural and physical problems) and will likely interact with various health and service professionals and supports throughout their life course with ABI. ONF works to address key health and social issues that require ongoing management and preventative action; to reduce their impact and prevent these co-morbidities from causing deterioration in functional gains of individuals with ABI. By approaching ABI as a complex chronic disorder across the life course, the intent is to allow people with ABI to optimize and maintain function, and remain physically and socially healthy as they move through the life course.

ABI as integrated systems

With direct and indirect costs of ABI in Ontario conservatively estimated to be \$2-billion annually, ABI is expensive, not only to those who sustain it, but to their families and the system as a whole. In the majority of cases ABI is for life.

Continuity of care is a key factor in sustaining what function has been recovered, and in providing the supports necessary to prevent decline and facilitate integration into the community and the ability to live fully with ABI.

By having an integrated system focus, ONF anticipates being able to inform regional and provincial policy-makers and those who plan for and provide treatment and services as to how to more effectively utilize scarce resources in the most appropriate and optimal manner for the long-term, both in terms of the health of people with ABI and their families, but for the health of the system.

ABI Research Programs:

- Community living supports for individuals and families
- Co-morbidities and sequelae
- Mild traumatic brain injury
- Translational research
- Children and youth
- Health to community systems

These programs do not stand independently of each other; rather they complement and can be informed by the knowledge and activity of the others.

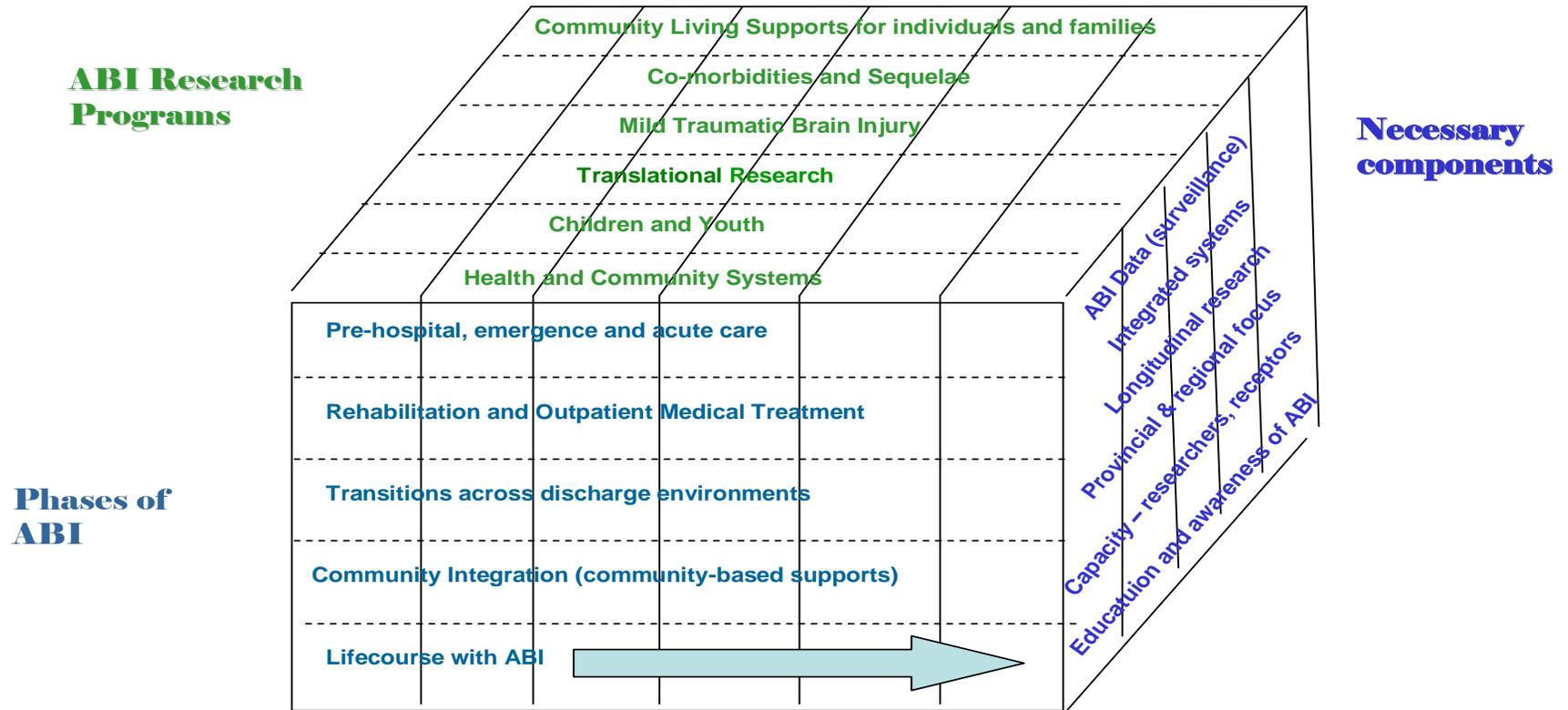
ONF's approach to ABI research and knowledge mobilization stems from a needs-based agenda through which key issues and gaps are identified through consumer, clinician and provider consults as well as previous research; and the use of essential data and surveillance that informs regional and provincial system issues.

Through the lens of ABI as integrated systems ONF utilizes its research to work towards building suitable and seamless care, appropriate utilization, and planning on systematic levels to address ABI as a complex chronic disorder across the life course. Both a regional and provincial focus is key in enabling local impact, cross-regional planning and evidence-informed provincial standards to be adopted.

As a field cannot exist without capacity, ONF approaches this on many levels, beginning with understanding the complexities and impacts of ABI through education and awareness in public and private spheres and in the community. Capacity will also focus on building the research field necessary to undertake essential ABI research and on individual, organization and systemic levels for those who are the receptors, users and implementers of the research.

The model on the following page describes the framework for the ABI Strategic Vision for 2020.

ABI Framework to 2020



Community Living Supports for Individuals and Families

Overall Program Goals: To maximize quality of life of survivors and their families through enhanced, coordinated and flexible community services

To improve integration of people with ABI into the community

Objectives

- To improve access to effective and comprehensive community services
- To determine and address what factors are critical to the successful reintegration of people with ABI
- To increase understanding of the needs of and differences across socio-demographic groups
- To improve services and supports for people with ABI as they encounter aging and life transitions.
- To increase community-based capacity to implement, deliver and sustain successful programs

Actions

- Develop inter-professional exchange and collaboration through the development of research to practice networks
- Work with community-based stakeholders to identify facilitators and gaps in regards to capacity, and to create opportunities for capacity building activity
- Better determine the needs of aging and life transitions with ABI through research activity, and initiate evidence-informed approaches to address these.
- Implement evidence-informed approaches aimed at improving reintegration into the community for people with ABI
- Utilize knowledge gained from ABI Health to Community Systems to work with key stakeholders to improve community living supports
- Work with partners in the Ontario Alliance for Action on Brain Injury and the Government of Ontario on the ABI Policy Framework, aimed at implementing key ABI supports and services across various Ministries.

Anticipated Outcomes for 2020

- Identification of facilitators and barriers to people with ABI accessing community services

- Development and evaluation of approaches to address access to community services
- Improved webs of regional referral and service provision
- Longitudinal studies that inform on the long-term picture of living with ABI

- Increased number of community-based services using evidence-informed approaches;
 - a) that build skills and function
 - b) that facilitate life skills for various transition points
- Stronger role of Community Brain Injury Associations
- Increased numbers of ABI survivors involved in their communities
- Better identification of at-risk clients and management of supports for them
- Reduction of inappropriate living environments

Potential and ongoing partnerships:

- Ontario Brain Injury Association and its 21 affiliated Community Associations
- Ontario Association of Community-Based Boards of ABI Services
- Local Health Integration Networks
- Ontario Alliance for Action on Brain Injury

Co-morbidities and Sequelae

Overall Program Goals: To improve quality of life by reducing the impact of co-morbidities and sequelae

Objectives:

- To better understand the impact of pre-existing morbidities on ABI and co-morbidities occurring following ABI
- To improve daily function of clients with ABI

Actions:

- Build on existing research syntheses to gather and generate as much potential evidence-informed knowledge about co-morbidities and sequelae.
- Develop ABI Clinical Research Networks in Ontario to strengthen the capacity to: examine and synthesize existing research; evaluate gaps in knowledge, and

undertake multi-centre research activity to address gaps in knowledge.

- Engage with various health professionals and professions in order to gain a better understanding of their practice challenges with the goal of supporting them in adopting evidence-informed practice to serve patients/clients with ABI
- Develop mechanisms to share knowledge with practitioners, administrators and policy makers to affect change in practice and policy.
- Incorporate knowledge gained regarding co-morbidities into the ABI Community Living Supports program so that changes can be made at system and program levels.
- Build relationships with organizations that focus on co-morbidities such as substance abuse, mental health, attention deficit hyperactivity disorder, etc to determine how to collaboratively address co-morbidities.

Anticipated Outcomes for 2020

- Better ways of identifying co-morbidities in people with ABI
- Increased number of evidence-informed interventions to address co-morbidities
- Increased number of evidence-informed approaches that result in improved function
- Uptake of evidence-informed practice by key stakeholders across Ontario

Potential and ongoing partnerships:

- Acute and Rehabilitation Centres
- Centre for Addiction and Mental Health
- Professional Associations (Medical, Rehabilitation, Nursing etc)
- Ontario College of Family Physicians
- ONF-REPAR Partnership
- Victoria Neurotrauma Foundation
- Community-Based ABI Services (OACBABIS)

Mild Traumatic Brain Injury

Overall Program Goals: To develop provincial standards to address identification, assessment, treatment and knowledge translation issues related to MTBI

Objectives

- To better understand the potential longer-term impact of MTBI across the life course
- To increase awareness and education of MTBI among health and social support professionals and the public
- To improve assessment, follow-up and coordination of treatment for MTBI and associated complications

Actions

- Develop research and mobilization activity to bring awareness that a concussion is a brain injury and that a significant proportion of individuals do not recover well.
- Build on existing relationships with organizations, professional associations and policy makers that work in the area of MTBI and establish new relationships with those that should be encouraged to better understand its impact.
- Develop longitudinal research to examine the longer-term impacts of MTBI across the lifespan.
- Establish Ontario as an international leader in addressing the treatment of complications associated with MTBI.
- Incorporate knowledge gained from the other ABI programs to establish better standards of assessment and follow-up of people who sustain MTBI.
- Collaborate with the Injury Prevention Program to address issues of return to play in sports injuries and reduce the risk of re-injury.

Anticipated Outcomes for 2020

- Improved follow-up of people who sustain MTBI
- Widespread use of a manageable, comprehensive and consistent definition of MTBI (that addresses the complexities of different ages)
- Improved identification of MTBI in ER and physician's offices
- Early identification of those that could be at risk of complications associated with MTBI
- Improved capacity to forecast treatment or service needs following MTBI
- Treatment guidelines in place for complications associated with MTBI
- Decreased health and psychosocial impact of MTBI on the individual and their family
- Decreased economic burden of MTBI
- Reduced occurrence of re-injury
- Increased use of age-appropriate return to activity guidelines (secondary prevention)

Potential and ongoing partnerships:

- College of Family Physicians
- Insurance Bureau of Canada
- Workers Safety Insurance Board and Institute for Work and Health
- School Boards
- Multiple Sports Associations
- Professional Association (Emergency Medicine, Nurse Practitioners, etc)

Translational Research

Translational research is seen as connected to all other ABI Research Programs and targets the novelty and innovation required to move late stage animal trials to clinical application. Translational research includes proof of principle studies for innovations in care and novel diagnostic and therapeutics designed to improve the provision of care across the continuum from acute injury to community integration.

Overall Program Goals: To improve understanding of the functions of the brain and how it responds to injury

Objective

- To foster promising approaches to improve diagnostic and therapeutic approaches

Actions

- Develop pre-clinical or clinical research activity that can promote and accelerate approaches to better understanding brain function
- Promote research that can improve methods for diagnosing severity and impact of brain injury as well as development of therapies to improve function
- Incorporate gaps identified in ABI Co-morbidities and Sequelae, and MTBI Programs in order to advance translational research activity to improve function
- Develop ABI Clinical Research Networks in Ontario that will link scientists with clinical experts in order to identify and undertake multi-centre research activity that will lead to clinical investigations
- Build relationships with research funders/organizations that focus on other disorders where there may be common research questions to address (i.e. Alzheimer's disease)

Anticipated Outcomes by 2020

- Increased availability of evidence-informed diagnostic and prognostic methods
- Increased number of clinical studies aimed at improving function
- Increased number of evidence-informed treatments and approaches to improve outcomes for people with ABI

Potential and ongoing partnerships:

- ONF-REPAR Partnership
- Baycrest Centre for Brain Fitness
- Victoria Neurotrauma Foundation
- Canadian Institutes of Health Research
- Neuroscience Canada

Children and Youth

Overall Program Goals: To better understand the prevalence and impact of ABI among children and youth. To improve quality of life of children and youth with ABI and their families

Objectives

- Increased awareness, identification and follow-up of ABI in the school system, particularly for 'at-risk' children and youth
- To improve understanding of the developmental trajectories of children and youth after ABI
- To identify the factors that enable successful transitions through development from childhood to adulthood
- To improve access to effective and comprehensive community services

Actions:

- Develop inter-professional exchange and capacity through the development of research to practice networks
- Build relationships with organizations, professional associations and policy makers that work in the area of children's health, human development and community supports
- Work with the Ministry of Education and School Boards to facilitate identification of ABI in the schools and to enable adequate follow-up from primary through to high schools.
- Develop longitudinal research to determine the longer term impacts of sustaining a brain injury in childhood or youth

- Develop research activity to understand the developing brain after injury and to promote approaches that can address challenges
- Implement and evaluate evidence-informed approaches to support young people with ABI and their families at various transition points
- Incorporate knowledge gained from other ABI programs to accelerate system, practice and individual level improvements for children and youth and their families

Anticipated Outcomes by 2020

- ABI accepted as a unique issue requiring different approaches for children and youth
- Improved range of services to support children and youth with ABI in schools
- Increased linkage between Ontario Ministries serving children and youth with ABI (MCYS, MED and MOHLTC)
- Longitudinal studies to follow-up on children and youth who sustain ABI
- Increased knowledge of the long-term impacts of ABI and specific needs at various ages
- Implementation of evidence-informed approaches to foster optimal development of young people living with ABI
- Increased ability of children and youth to participate and function in the community
- Improved independence of young adults with ABI and ability to take on adult roles in the community
- Reduced stress on families of children / youth with ABI
- Decreased economic burden for families of children / youth with ABI

Potential and ongoing partnerships:

- Children's Treatment Centres
- CANCHILD
- Community Care Access Centres
- Ministries of Children and Youth Services and Education
- Local Health Integration Networks
- Provincial Council on Children's Health

Health to Community Systems

Overall Program Goals: To better understand and connect health and community supports for ABI throughout the province within the regionalized model of the LHINs

Objectives

- To support the development of seamless system transitions for people with ABI from point of injury through to their living environments
- To improve the ability to identify current needs and forecast future needs, and provide service according to those needs (individual and system)
- To identify and address regional inconsistencies of health and community supports to people with ABI
- To study the potential of adapting successful approaches used with other populations to ABI systems of care

Actions:

- Develop relationships with LHINs to discuss and plan for how the work of ONF can support improvements to access, coordination, delivery and utilization within and across LHINs.
- Continue to augment ABI Dataset to capture information from the health sector as well as various community agencies.
- Utilize ABI Dataset and Systems Analysis to examine patterns in injury service, system transition, access, utilization and coordination.
- Utilize the above knowledge as well as that gained from other ABI programs to inform on system changes at the regional and provincial level.
- Initiate research to improve classification of brain impairment as it relates to outcome, in order to foster systematic methods of forecasting and providing supports for people with ABI.
- Develop relationships with associations and organizations providing service and support to people with ABI and their families, in order to share knowledge, create capacity and build partnerships for implementing evidence-informed approaches.
- Work with partners in the Ontario Alliance for Action on Brain Injury and the Government of Ontario on the ABI Policy Framework, aimed at implementing key ABI supports and services across various Ministries.

Anticipated Outcomes by 2020

- Increased coordination of ABI services and supports within and between Ontario's LHINS to support transitions from acute and/or rehabilitation settings to living environments
- Establishment of province-wide standards for systems that treat and serve people with ABI

- Development of processes that enable people with ABI to loop back into the system when needed.
- Establishment of a centralized ABI data-set (registry) to track service utilization, trajectories and outcomes
- Province-wide standards in place to measure impact and prognosticate outcomes of TBI and to forecast needed supports
- Increased use of strategies to better support people with ABI living in remote or northern communities.

Potential and ongoing partnerships:

- Ministry of Health and Long-Term Care
- Local Health Integration Networks
- Community Care Access Centres
- Institute for Clinical and Evaluative Sciences
- Insurance Bureau of Canada

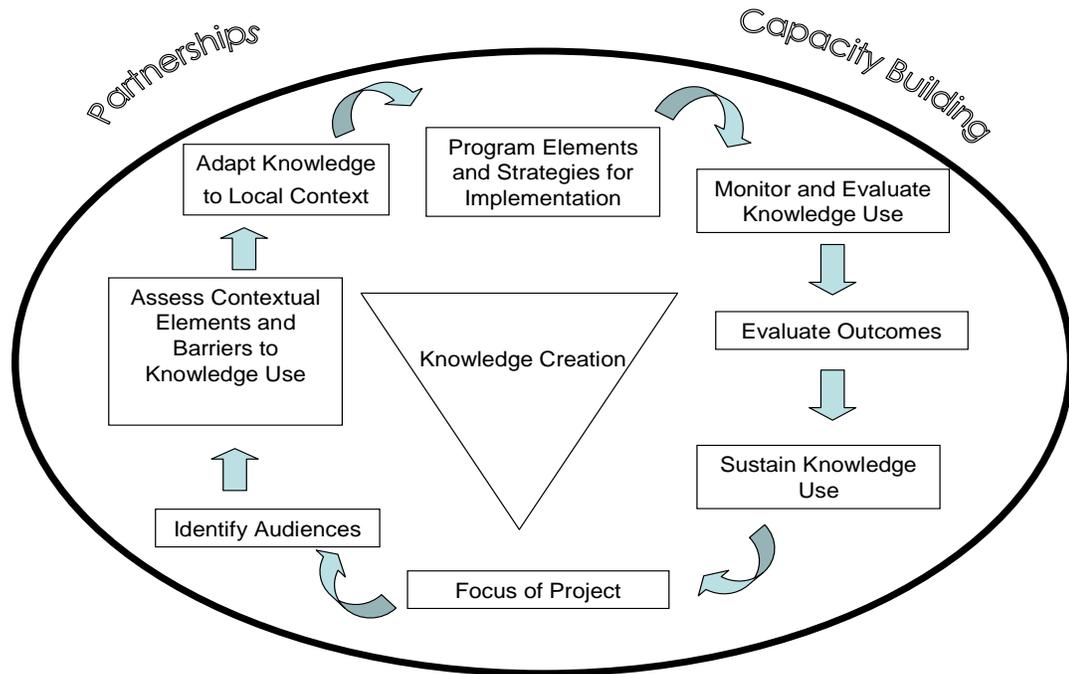
Knowledge to Action

An integral component of each of the ABI research programs is ONF's model of integrating knowledge creation with its mobilization. Each research program is approached through this model, where knowledge creation enables the identification and involvement of key audiences, and mobilization activity aims at identifying individual and system barriers in order to carefully plan for and build implementation of practice. This continues with concerted strategies to monitor the adoption and outcomes of this implementation, and a deliberate approach towards sustainability of practice and careful exit for ONF.

The following model fairly closely approaches the ONF model of Integrated Research and Knowledge Mobilization and can be used to guide the ABI activities for Vision 2020. The model will work within and strengthen the systems in which ABI is addressed, the partnerships that can be formed, the availability of data, and the capacity of health practitioners and deliverers of service, their organizations and communities to implement and sustain evidence-informed ABI practices.

The model will work within and strengthen the systems in which ABI is addressed, the partnerships that can be formed, and the capacity of practitioners and deliverers of service, their organizations and communities to implement evidence-informed ABI practices.

ONF Approach – Knowledge to Action



Based on a model developed by Graham et al, 2006