Policy Implications for Persons with Neurological Conditions

Prepared for the Ontario Working Group of Neurological Health Charities Canada by Change-Ability, Inc.

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Introduction

NeuroScience Canada estimates that one in three Canadians will experience a brain condition in their lifetime – a neurological or psychiatric disorder, disease or injury for which there are limited treatments and no cure. These are conditions that span every age and stage of life. Their cause is often unknown, yet as they take hold of people’s lives, they result in increasing impairment for those with the condition, and have challenging impacts on families and caregivers. For individuals, families, communities and Ontario, the health, social and economic costs of neurological conditions are enormous.

Neurological conditions have historically been considered on a condition-specific basis, with health charities advocating individually to government. Until now, neurological conditions have not been approached as a category of illness in which there are a significant number of shared attributes and care needs, cutting across the range of differences between conditions.

In 2008, health charities representing Canadians with a variety of brain and neurological conditions came together to form a coalition. Not precluding work by individual coalition members, Neurological Health Charities Canada (NHCC) was born of the recognition that the needs of the millions of Canadian families who deal with the many chronic diseases, injuries and conditions that affect the brain can also be supported through cooperative effort.

Over the past year, the NHCC has consulted extensively with the Health System Strategy Division (HSSD) of the Ontario Ministry of Health and Long-Term Care (MoHLTC) to identify common issues facing Ontarians with neurological conditions. The resulting report is the product of over a year of consultation and stakeholder engagement — amongst the full range of those involved with neurological health charities in Ontario.

The purpose of this project, and the role of Change-Ability Inc., is to develop a set of long range recommendations that would be catalysts for, and form the basis of, an integrated Ontario Brain Strategy. The recommendations within this report support the achievement of government priorities (health, social and economic) and joint action across the government, NGO and private sectors — by identifying opportunities to leverage existing resources and new investments for greater impact.

Change-Ability’s facilitation role utilized long-range scenario planning (LRSP), to explore long-range strategic and policy options to address the complex challenges faced by Ontarians living with neurological conditions. LRSP is a mixed discipline approach to identifying long-range robust strategic themes, through the collaborative analysis of plausible future scenarios with diverse partners within and outside the health system. The focus of LRSP is on identifying options that will result in
the type of high quality, robust and sustainable programs and services which merit financial and social investment.

Durable social change will involve public policy change some of the time. But it will also involve public education, public discourse, and framing the needs and interests of those with neurological conditions in terms of their shared needs and interests, and not the differences in their diagnoses. What would we see and do as a society now, if we could see the long-term consequences of how our current inaction and ineffective actions will affect so many Ontarians? The development and implementation of an Ontario Brain Strategy is a clear role for government leadership in the arena of social innovation.
About Long-Range Scenario Planning (LRSP)

Long-Range Scenario Planning (LRSP) recognizes that the future cannot be predicted. However we need to make long-term choices informed by strategies that are robust enough to enable progress in the face of uncertain change. LRSP is not about looking into a crystal ball or writing science fiction; scenario planning is about thinking of the future and acting today to shore up crucial competencies and embark on productive pathways. Ultimately this planning mindset is optimistic and opportunistic: building on the belief that we are not lost to the whims of indeterminate change, and that our current choices and actions make a difference. The LRSP process necessitates a collaborative effort which engages opinion leaders, practice leaders, planners and decision-makers across many different systems, and produces outcomes which are informed by subject matter experts.

Between late 2009 and early 2010, multi-sector stakeholder consultations, “future-scanning”, and policy explorations took place to support a long-range scenario planning process focused on Ontarians living with neurological conditions. This LRSP process informed development of this report. The approach included the following:

1) Scanning the Future Horizon – Identifying Trends and Drivers

The first stage of LRSP is anticipating and thinking about what factors and trends might influence the nature and impact of neurological conditions (and the persons who live with those conditions) over a long-term period. For the purposes of this scenario planning exercise, a twenty-five year framework was chosen. This requires identifying and reflecting on emergent Political, Economic, Socio-cultural, Technological and Legal trends in the broader social environment (PESTL), with 2034 as a target date. Further consideration is given to the implications of these trends (see Figure 1), both positive and negative, specifically exploring challenging issues that might pervade the future of neurological conditions.

The goal of this process is not prediction, or consensus-building around identifying trends, opportunities or threats. Instead, the desired output is to break down old patterns of thinking and to test prevailing assumptions. This supports the next stage: building a variety of different plausible social contexts – or “scenarios” – in which to consider the future.
Figure 1: PESTL Themes
2) Scenario Building

Drawing from discussions and implications of the PESTL analysis, a series of contextual themes are identified. Against these themes, stakeholders are consulted to identify pervasive issues and systemic problems and paradoxes which might impede stakeholders’ progress, and block their desired futures. Working with these core issues, and set against the broader context, a number of plausible narrative futures/scenarios are developed. The scenarios reflect divergent trends and drivers: unlike some scenario building exercises, the construction of four scenarios avoids the approach of creating simple dualistic “good” and “bad” futures. The methodological function of the scenarios is not to pick a desirable end point, but to compose a variety of possible futures which call attention to variables, events and actions which have both positive and negative implications. The scenarios are not designed to be inclusive of all possible issues, but to represent a selection of plausible future issues, and provide stakeholders with a common starting point for discussion.

Stakeholders from across the spectrum of neurological disorders and their respective care systems who were involved in the LRSP consultation sessions were asked to identify and discuss what they found attractive and positive in each scenario, which aspects of the scenario generated cause for concern, and then to discuss various ideas and solutions. This feedback was used to build the next stage of the LRSP process: the identification of robust competencies and strategic directions — pathways forward in uncertain contexts.

In brief, the four scenarios developed and discussed at the NHCC stakeholder consultations were:

**Family on Remote Control**

The story of two daughters and their elderly mother who tries to live independently while suffering the effects of aging and a neurological condition. Key elements of the story highlighted technology, including electronic health records, remote technology for home monitoring; a coalition as a lobbyist; a strong private sector influence; and the mass customization of pharmaceuticals.

**As Strong as Our Weakest**

A narrative describing a man in mid-life suffering the early effects of ALS, and the role of his informal caregiver. Key elements of the story reflected caregiver insurance; repercussions of medical technology’s advancement; open research code and protocols; alternative forms of employment insurance; health promotion and disease prevention; and the migration of international charities into Ontario and Canada.
Neuroseal of Approval
The story of a young woman suffering the effects of MS while striving to remain in the workplace. Key elements of the narrative included a coalition actively pursuing social marketing and social enterprise; tax credits and incentives; multi-ministry involvement; the labour market and employee value; workplace flexibility; and the marketing and use of assistive devices.

Stigma Then, Normal Now
A narrative describing an adolescent man experiencing the cognitive and physical effects of a neurological condition and how the education system of the future responds. Key elements of the story included the use of technology to reshape school curriculum and learning methods; the use of population forecasting models to allocate health funding; networks of best practice; a voucher system for purchasing services and devices; and strong community volunteerism.

3) Identifying Robust Themes
The third stage of the LRSP process is accumulating the feedback drawn from the scenario discussions; categorizing themes; counting the frequency of themes; and evaluating theme distribution across scenarios. A robust theme is one that cuts across most or all scenarios, with the embedded assumption that this theme is highly likely to be important regardless of how the future unfolds. Building strategy on a robust theme implies that such a strategy will be relevant and flexible in the face of uncertainty. The scenario feedback is also used to identify consistent themes which appear to be opportunities (i.e. to be an early adopter or catalyst for significant change), or negative themes that indicate threats (i.e. which may require the building of strategic response to divert or reduce impact).

In this LRSP process, a total of ten robust strategic themes were identified in neurological system stakeholder consultation sessions. These themes were further validated through a survey of expert advisors. Five themes were identified as primary and robust: Personalizing Support and Participation; Harnessing Knowledge; Mobilizing Technology; Shifting the Culture; and Supporting Caregivers. An additional five themes attracted significant support, particularly in terms of representing “enabling” conditions or strategies which would help facilitate the five primary themes. These included: Taxing and Funding; Integrating Systems; Designing the Built Environment; Engaging the Private Sector; and Continued Collaboration (see: LRSP Robust Themes for a brief description of each theme).
From these themes, a Working Group (representing the Ontario interests of Neurological Health Charities of Canada (NHCC)) identified three strategic priorities (referred to hereafter as “streams”) in which to focus their efforts. Those streams are: Integrated Comprehensive Health Care & Community Support; Social Innovation; and Education for All.

These three streams are rooted in the themes identified through the scenario planning process (see Figure 2), and are the source for the strategic priorities explored further in this report, in the section which details Policy Implications.

4) Exploring Policy Implications
The final stage of the LRSP process is exploring the policy implications of each theme. Over the course of each stage of the LRSP process – from trend and driver analysis to the identification of themes – stakeholders generated a broad array of ideas and solutions. At the policy implication stage, these ideas and solutions were linked to the appropriate themes and system challenges. The key criteria for selection were two questions:

1) Does the idea align with the robust themes and system challenges?
2) Is the idea strategic in implication rather than operational?

Further amplification and elaboration of each consultation-generated idea was undertaken in collaboration with the NHCC Working Group.

The development of policy implications helps identify key strategic destinations, and introduces possible pathways for reaching these destinations starting in 2010. From this knowledge base, an overall strategy for persons with neurological conditions that is future forward and future flexible can be constructed.

The World of Neurological Conditions in 2010
The term “neurological condition” provides a simple label that actually encompasses a wide array of diseases and disorders, some physical in effect and others more significantly cognitive or behavioural. Neurological conditions can emerge in a variety of ways at any stage of life, from birth to end-of-life and everything in between. Trajectories can vary from sudden onset conditions (e.g. brain injury), to intermittent and unpredictable conditions (e.g. early Multiple Sclerosis), progressive conditions (e.g. Parkinson’s) or stable long-term neurological conditions linked to developmental changes or aging (e.g. post-polio syndrome). The experience of a mid-life person with Amyothrophic Lateral Sclerosis is different from an older adult with Parkinson’s disease, and each of these experiences are distinct from that of a young person with epilepsy. Due to prevalence, some conditions are more familiar to Ontarians than others because there is an increased likelihood that one will have a family member or friend experience particular neurological limitations. Conditions which occur with less frequency are
unlikely to directly, or even indirectly, affect the average person. With such diversity in prevalence, population, symptom, social effect, and trajectory one might ask: why use a simplistic label such as “neurological conditions” at all?

The first answer is that every neurological condition has a common variable: the brain. All neurological conditions have a vested interest in the basic science that expands knowledge and creates the capacity to positively affect neurological challenges. Human science understands the brain’s essential role in communicating life functions to the rest of the body, and further interpreting signals from other parts of the body through systems of feedback and response. For the seemingly simple act of walking, the brain is the central command centre. It determines where one wishes to walk and why and then sets off a complex physiological process. Yet, with a neurological condition, not only might the physical process of movement be affected, so might the cognitive act of where and why. When the brain is affected the social consequences on the experience of living can be profound.

The second answer is that every neurological condition has a common point of interest: integrated medical and social support systems. Each distinct condition is dependent on large and complex health and social systems of generalized knowledge and services, with the capacity to accommodate specialized expertise and functional requirements. While the bodies of knowledge and expertise vary for each condition, system design pre-requisites are often either similar or identical for all conditions.

The fundamental question in 2010 is how effectively our health, education, workplace, social innovation and social care systems are addressing the needs of persons with neurological conditions. In listening to professionals, families and clients, the answer would seem to be not particularly well, despite the efforts of dedicated professionals and caregivers, both informal and formal. The same issues are raised repeatedly and consistently, cutting across conditions (see Table 1).

The emergence of services and supports for persons with neurological conditions has been episodic and lacking an overarching “system” vision, in terms of approaches, standards and funding. The net result is a distribution of service nodes which are not always well-matched to client needs (family health care, specialty clinics, home care and community support). There are inconsistent connections between these nodes, and considerable differences in terms of availability and accessibility. The need for system redevelopment and redesign is a common interest amongst all neurological conditions.
**Table 1: Key Strategic Issues (Abbreviated)**

| Family Health Care | · Family health care is slow in recognizing early symptoms, assessment/diagnosis, and prompt referral for specialty care when necessary  
| | · No managed system of standards and services for referral – inconsistent mix of choices and uneven awareness of choices  
| | · Inconsistent knowledge in how to manage ongoing care  
| Specialty Care | · Long wait lists  
| | · Uneven regional distribution of specialists and specialty clinics and in some cases no specialty clinic (e.g. adults with spina bifida)  
| | · Inconsistent models of care — some medical only, some multidisciplinary, some disease focused, others functionally focused  
| | · Clinics within hospitals subject to uncertainties in funding and support under global budget  
| Community Support | · Inconsistent support and care standards  
| | · Few community agencies with dedicated knowledge and mandate for neurological conditions  
| | · Large burden on family and other informal caregivers  
| | · Administrative processes (e.g. “closing” & “re-opening” files) not aligned with trajectory of many conditions  
| | · Palliative care geared to cancer population with reduced access and flexibility for neurological conditions  
| Systems and Navigation | · Evolution of services has been ad hoc and piecemeal, lack of a connected system  
| | · Little provision of case management and navigational support  
| Social Inclusion — Living | · Cost challenges for home modifications, equipment and supplies, and assistive devices; further restrictions on changing needs; a managed system rather than choice-based  
| | · Lack of availability of accessible, affordable housing and supportive housing  
| | · Unstable or inadequate income support for persons with neurological conditions and/or their families  
| | · Long-term care facilities not age appropriate for younger persons  
| | · Education system not adequately identifying neurological conditions  
| | · Inconsistent knowledge of neurological conditions among teachers and support staff  
| | · Little flexibility in creating adaptive environments for learning  
| | · Lack of awareness by employers  
| | · Few available employment supports  
| | · No system of incentives and supports for employing persons with neurological conditions  


Social Inclusion – Connection and Participation

- Inadequate transportation (particularly accommodating cognitive challenges)
- Poorly designed built environments to accommodate impairments
- Social isolation and poor access to social resources

A third commonality amongst neurological conditions are the social consequences of experiencing a profound change in how one is engaged in modern society and can (or cannot) participate as a valued citizen: the opportunity to have friends and close social connections; the right to have a job or other meaningful activity; an accessible home. These are the fundamental building blocks commonly understood as essential to a positive life — the expected outputs and outcomes created by a modern political economic system. When these opportunities are not present, it indicates a need for accessible, integrated medical care and social support, as well as a shift in our social infrastructure — to create meaningful opportunities for a normalized existence as friend, neighbour, colleague and fellow citizen.

These three commonalities — the physical locus (the brain), the need for integrated health care, social supports and educational systems and the shift in social situation — are just a sample of the shared interests of “neurological conditions”. Shared interests, like those identified here, can form the basis for shared strategic directions and system solutions. Yet in 2010 the linkages, collaborative ties and working relationships across neurological organizations incompletely reflect common interests and may have been underutilized prior to the formation of the NHCC.

Knowing the problems of 2010 is only the first step towards finding solutions. The next question is determining the strategies and directions for re-shaping our systems (or non-systems) to address the health care, educational needs and social rights and entitlements of persons with neurological conditions. Stakeholders from every part of the broader neurological community have come together to try to find common cause and a shared path forward. It is their sincere hope that their efforts may be recognized, supported and joined by the government of Ontario and its relevant ministries.

So what are the strategic solutions and approaches that are flexible, resilient and adaptable, and which can be implemented jointly in the face of change and uncertainty?

**LRSP Robust Themes – The Catalysts of Change**

The World Health Organization’s International Classification of Functioning, Disability and Health (2001) repositions the prevailing view on “health” and “disability”. Starting from a perspective that health is more than the absence of disease, and that a person can be “healthy” even while...
experiencing an adverse disease or disorder, the ICF advocates for recognition that while every human being can experience an impairment (“problems in body function or structure such as a significant deviation or loss”), an impairment is not the same as a disability. A disability is “a complex relationship between an individual’s health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives”. This definition takes the perspective that disability is a social outcome rather than a medical or biological dysfunction. In other words, the failure to adopt enabling social policies to accommodate a physical and/or cognitive limitation is the key source of “disability” – not the limitation or impairment in and of itself.

From this perspective, discussing a system for persons with a neurological condition means discussing far more than a discrete set of health care services. It means looking at an integrated set of structures and processes, cutting across social sectors such as health care, education, transportation, housing, social services and social innovation. Founded on an understanding of the social determinants of health and well-being across the life course, such a system is geared to promoting the highest level of health possible, even in the presence of a limiting neurological condition — improving the “circumstances in which the individual lives”.

Through the three stages of LRSP, a series of robust themes were identified — catalysts that seem likely to shift (and make cohesive) the current scattering of services and supports. The majority of stakeholders viewed these themes as plausible drivers of change in an uncertain future.

**Personalizing Support and Participation**

While individuals with neurological conditions and the people who support them share many common challenges, there will always be specific needs that are diverse and unique. Advances in genomics and pharmaceuticals are seen as likely to only increase the need and demand to give individuals flexibility and control over their own care and treatment. Personalization issues span workplace design, quality of life decisions, control of and choice in care-pathways, educational opportunities, service delivery, transitions across life stages, and diverse social/family structures. Consequently, there is a need to make medical care, supports and services adaptable, so that people with neurological conditions can direct their care as they see fit, participating in their communities, workplaces or schools according to their individual abilities and limitations. By implication, “personalizing” support refers to a person-driven system. This is a system in which the clients/patients and their families are not passive agents in receipt of services, but rather in direct control of decisions for medical care, social supports and shaping their living environment. Health care and other human service professionals are then understood as acting as collaborative partners — helping to make informed decisions which address their needs and preferences.
Shifting the Culture
This theme includes issues of stigma and normalizing neurological conditions — shifting from an illness orientation to a system of health. Ultimately, this broad and comprehensive socio-cultural shift is about changing perceptions, and enacting the policies and tools that facilitate meaningful change. Public values and attitudes, awareness and education feature prominently in this theme. The roots and role of charities are also considered, both as potential barriers that constrain options as well as a source of opportunity for exploring new methods of revenue generation, service delivery and advocacy.

Harnessing Knowledge
Harnessing knowledge refers to designing knowledge systems which allow health professionals, organizations, caregivers and individuals with neurological conditions to access and use reliable medical and decision support information. Issues raised in this theme include privacy and control over information as well as equitable access and funding. This theme explores the potential benefits of online health information and social networks for individuals with neurological conditions and their caregivers, as well as looking at the potential implications of this for neurological health charities and their knowledge holdings, research and information systems.

Mobilizing Technology
Most stakeholders consulted during the LRSP process shared the opinion that the growth and influence of technology will be heightened in the future. “Technology” was seen to include those assisted living technologies which support smart homes, accessible workplaces, and flexible transportation systems. These technologies offer great promise, however, their costs are potentially high and the return on investment in comparison to low tech solutions is often poorly understood. Concerns surrounding these technologies include equitable access and funding, individuals’ and organizations’ acceptance and utilization as well as the social and physical limitations of relying on technologies. Consultations emphasized that this theme needs to be understood as a complement to personalized support (including “human touch”) and not as a replacement. The core consensus for strategy development is that technology is not the solution, but rather, technology enables solutions.

Supporting Caregivers
A family member or friend is often central to the lives, and quality of life, of persons with neurological conditions. The support (or lack of support) provided to these informal caregivers can significantly
impact the legal, financial, knowledge and social support needs of the individuals in their care. Issues raised in this theme include: appropriately valuing and compensating caregivers; providing for flexible exits from and re-entries to the labour force; respecting diverse family and social relationships between caregivers and the people they support; education and health literacy; caregiver competency; and the rights and responsibilities of caregivers.

**Integrating Systems**
This theme is about integrating organizational systems that are typically fragmented, including: provincial level ministries and levels of government; health professionals and charitable organizations; and the interplay and collaboration between NGOs (non-governmental organizations) and government at the levels of both public service and public policy. This theme features a holistic approach to individuals with neurological conditions, through: streamlined funding models, integrated service delivery, shared clinical networks, and “wrap-around” care.

**Designing the Built Environment**
Designing a built environment that is sufficiently accessible and flexible to accommodate the diverse and dynamic needs of people with neurological conditions is a dynamic catalyst with the potential to either reduce or increase “disability”. “Built” refers here to the fact that this environment is within human control. The issue is not only how to build the environment in a health positive way, but how to develop the social will and economic capital to do so. This includes flexible and affordable housing, transportation systems, workplaces and communities.

**Engaging the Private Sector**
This theme acknowledges that the private sector will likely continue to be a hub of research and development. However, the effective development of a neurological strategy includes the need to protect against concerns about private sector domination and the dangers of self-interest. There is an opportunity to identify our shared market interests that span the breadth of differential diagnosis and specific conditions to stimulate the development of higher quality and lower-cost products and services. Also featured in this theme is the need to encourage employers to provide the accessible workplaces and flexible work arrangements that allow people with neurological conditions to contribute in the workforce according to their abilities.

**Taxing and Funding**
The taxing and funding theme is about the fiscal resources that enable reasonable choices and options, and the various ways in which public sector services and private sector markets can be configured to enhance quality of life. This theme includes approaches that support individuals with
neurological conditions in: directing their own care; creating employment opportunities; and providing incentives for investing in an accessible built environment. The need to better understand the cost-benefits of initiatives across ministries and levels of government also features in this theme.

**Continued Collaboration**

There are many potential benefits and pitfalls of collaboration amongst diverse organizations. On one hand, there is broad recognition that thinking beyond organizational boundaries to specific shared causes will be more effective at harnessing knowledge, as well as influencing public awareness, government agendas and private sector investment. On the other hand, there is wariness of diluting brand, financial fairness, and the ability of smaller causes to be successful within a single overarching entity. It is essential to recognize that better forms of collective action or organization do not require merger/amalgamation and that most future thinking emphasizes the strength of networks and partnership rather than a singular hierarchical organization.
Figure 2: Streams of Work, System Design Elements & Robust Themes

Integrated Comprehensive Health Care & Community Support

1. Engaging Family Health Teams in Neurological Care and Connecting Specialized Care
   - Strategic Option – Building Neuro-Awareness in Family Health Care
   - Strategic Option – Connecting Specialty Knowledge Through Communities of Practice
   - Strategic Option – Connecting Systems and People Through Technology

2. Creating Choice & System Navigation
   - Strategic Option – Promoting the Right Information for Personal Choice
   - Strategic Option – Innovation in System Navigation

3. Strengthening Community Support
   - Strategic Option – Shaping an Integrated System of Community Support
   - Strategic Option – Caring for Caregivers

Enhancing Social Inclusion – Income, Employment, & Housing

4. Enhancing Social Inclusion – Income, Employment, & Housing
   - Strategic Option – Raising the Bar on Income
   - Strategic Option – Employment for All
   - Strategic Option – Housing for All

Social Innovation

5. Fostering Technology & Research
   - Strategic Option – Creating a System of Technology
   - Strategic Option – Advancing a Research Strategy for the Brain

6. Building a Neuro Partnership
   - Strategic Option – A Sustainable Partnership for the Future

Education for All

7. Designing the Built Environment
8. Integrating Systems
9. Engaging the Private Sector
10. Taxing and Funding

Personalizing Support & Participation

11. Shifting the Culture
12. Mobilizing Technology
13. Supporting Caregivers
14. Harnessing Knowledge
Policy Implications for Building an Ontario Brain Strategy

The identification of robust themes establishes the foundation for the catalysts and drivers for change which provide the basis for strategic transformation. Although derived from a process in which stakeholders were asked to think about the future twenty-five years from now, the implication is not that action is a twenty-five year project. Instead, it helps to create confidence that the strategic actions taken today are well aligned with the future as we can best anticipate it over the next decades.

In this section, we refer back to the original list of system design elements and problematic issues identified in Table 1. Placing the system design in the context of future catalysts and drivers is used to help identify the policy implications and strategic ideas that can positively affect the development of an inter-sectoral and integrated system for persons with neurological conditions — that is, the catalysts that help shape the opportunities, and create levers for change.
Stream of Work: Integrated Comprehensive Health Care & Community Support
The need for a better integrated system is one of the most dominant themes emerging from the long-range scenario planning consultations. In almost every positive vision of the future, integration was present. In the stories of excellent care whenever received, integration was present.

A resolve to “do better” in integrating the client’s experience of the health system can: improve patient outcomes; introduce new opportunities for financial savings (e.g. consolidation of back office functions); and play an extremely strong role in perceived health system quality. The presence of well-trained specialists and experts are necessary in the crafting of an improved future, but their presence in communities and in the lives of those struggling with neurological conditions is too often experienced as siloed and “fractured”. A well-integrated system has the potential to be efficient, effective and of high quality, spanning the full continuum of the challenges and experience of daily living – whether that be in a school, a workplace, or the broader community.

Integrated care is an area where minor changes may yield significant results, where adoption of best practices in integration, client communication, and adoption of a client-centric option-based approach to care (e.g. telemedicine) has the potential to dramatically alter perceived and actual system quality, flexibility and strength.

Determinants of health span education, income, social inclusion, literacy, opportunity, adequate shelter and much more. Individuals with neurological disorders benefit enormously when they are wrapped in a caring and supportive community with their own opportunities to make a lifelong contribution wherever possible.

Part of the challenge is the de-stigmatization of these neurological conditions, the development of a broader base of understanding of their frequency and normality in the population, and the recognition that a medical response is a necessary one but not a sufficient one.
System Design Element: Engaging Family Health Teams in Neurological Care and Connecting Specialized Care

In 2010, Ontario’s Family Health Team model is transforming how primary health care is organized and delivered. The past five years have been characterized by a movement away from a focus on a single practitioner to an approach that incorporates a wider set of disciplines and working relationships. No less significant is the evolution of an organizational platform that holds the capacity for strengthened system management by interconnecting the parts of the health care system. One well recognized initiative that will assist this process will be the electronic health record (EHR), the objective of which is to seamlessly transfer and manage patient information.

Family health care and specialized neurological care are two issues that are fundamentally linked in designing a system that provides appropriate neurological care. While the function and body of knowledge of each care model remains unique, through the lens of system development they should be viewed in terms of linkages and connections rather than as distinct and isolated nodes — to create a flexible system of knowledge that cuts across the complimentary domains of on-going “whole person care” and specialty expertise.

Progress on this area of system design will require the collaboration of the Ontario Ministry of Health and Long-Term Care, the Ontario Association of Family Health Teams and the Ontario Medical Association, to explore and implement best practices in system navigation and an integrated care pathway.

Strategic Option – Building Neuro-Awareness in Family Health Care

Family health care professionals often lack the specialized knowledge required for early recognition, assessment, referral and on-going health care management of neurological conditions. Filling this knowledge gap requires building neuro-awareness into family health care. Evidence on knowledge exchange/transfer indicates there is no single way to effectively communicate best practice knowledge and understanding. Instead, a variety of approaches and mechanisms are required; each of which must be viewed as “legitimate” in the eyes of practitioners and further seen as enablers rather than time-consuming tasks added to the busy family health practice day. At a macro-level, this means building a perception of the priority and value of neurological care. At a more micro-level, this knowledge exchange is accomplished by mobilizing technology to effectively place knowledge and evidence at practitioner’s fingertips to guide their decision-making.

- Explore with the Canadian College of Family Physicians the development of a program of CMEs on neurological conditions across all phases of family health practice – early recognition, assessment and diagnosis, referral to specialists, availability of neurological resources (e.g. Accomplishing for neurological conditions results similar to recent “memory clinic” advances in dementia care, see PubMed: “Enhancing Dementia Care”).

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Create a joint partnership with leading organizations in the field of electronic health innovation (e.g. Centre for Global eHealth Innovation, Ontario Brain Institute, OntarioMD) and neuroscience research to develop and trial online easy-to-use decision-tree tools that enhance assessments and diagnosis in Family Health Team environments.

**Strategic Option – Connecting Specialty Knowledge Through Communities of Practice**

Over the past ten years, there has been a movement towards facilitating new ways of organizing and distributing research and clinical expertise through knowledge transfer. Stepping beyond the bricks and mortar of an office or an institution, the process of networking is evolving across health care. Specialized knowledge cuts across multiple professionals including neurologists, pediatricians, occupational therapists, physical therapists and others. The knowledge is often diffused and difficult to find or quickly access. There is no single access node.

“Communities of practice” refers to groups of professionals informally bound together by shared interest and expertise in a network of joint enterprise (Wenger and Synder, 2000). Such communities can be seen in private sector industry (e.g. information technology, manufacturing, financial services) and represent an evolving trend in health care in other jurisdictions. For example, the Canadian Partnership Against Cancer is taking first steps to implement a community of practice model (Bentley, Browman and Poole, 2010). Communities of practice build upon existing expertise that is frequently unevenly distributed and disconnected, and helps to build a systematic approach that explicitly marks visible pathways and points of access. Moreover, the community of practice approach can establish the human capacity upon which innovative technological solutions can be founded.

- Build communities of practice through a systematic approach of:
  1. Identifying and mapping existing neurological expertise across the province;
  2. Reviewing existing capacity and referral patterns;
  3. Assessing the existing funding sources and limitations (e.g. hospital global budget, OHIP billing);
  4. Facilitating the creation of formal communities of practice including referral processes and collaborative knowledge sharing (e.g. establishing sessional fees for general neurologists to partner and work regularly with Family Health Teams (FHT); replicating “memory clinics” across Ontario's network of FHTs);
  5. Encourage and support the Ontario Ministry of Health and Long-Term Care to identify community of practice funding models that are stable and enhance accessibility for direct multidisciplinary care, and facilitate...
collaborative advice tools with other health care providers (e.g. electronic communication and consultation)

**Strategic Option – Connecting Systems and People Through Technology**

In 2010, “social innovation” is moving beyond the realm of academic papers and speculative experimentation towards the implementation of service delivery models and approaches that innovatively adopt new technology. The use of telecommunication and other forms of electronic exchange is not new in and of itself. The use of teleconferencing to link rural and remote areas in northern Ontario with clinical expertise in southern Ontario has evolved over the last decade and a half to become a legitimate form of medical practice. So what is new and different? One evolution of social innovation is that the form of technology is shifting from the slow and obtrusive to the rapid, mobile and ubiquitous. Less and less, technology binds one to a room. Personal Assistant Devices can speed the exchange of clinical questions and information. Expensive pre-scheduled screen time can increasingly be transformed into desktop and mobile solutions with no time constraints. These changes increase the potential for easy adoption in day-to-day care across the province, in urban and remote settings alike. But, critically, the adoption of technology still tends to be secondary — an exception in the care process. In other words, technology is not being fully exploited as an effective tool that can transform the lines between generalized and specialized care.

In the UK, the **NeuroResponse** initiative is a social enterprise – currently focused on MS – that is comprised of three functions designed to enhance access to prompt and appropriate care and advice. It has passed the proof of concept and pilot project stages, and is testing their socially innovative business model, which uses:

1. NeuroDirect – telephone triage/advice line service staffed by expert MS nurses;
2. NeuroMail – email advice service that GPs can use to contact a consultant neurologist;
3. NeuroView – video clinic linking an expert neurology team with the patient and local clinical team.

Initiatives such as NeuroResponse provide a modern template for how much of health care might be delivered in the future – allowing technology to improve accessibility and quality through a blended systematic approach to connecting knowledge in all its forms.

- Create a business case and prototype for a NeuroResponse network system that integrates technological solutions with communities of practice, including a System Navigation portal (see “Creating Choice and System Navigation”) and social network site (see “Social Inclusion – Connections and Participation”).

- Investigate connecting a NeuroResponse system with existing platforms such as TeleHealth or Mental Health Service Information Ontario.
Align with emerging social innovation movements (e.g., MaRS Centre for Social Innovation) to evolve partnerships for technology development/adoption as well as exploration of social funding approaches and sources, leading to a competitive RFP bid for NeuroResponse system construction.

System Design Element: Creating Choice & System Navigation

A person-driven system of options and opportunities maximizes the potential for choice: allowing persons to align their care decisions with their needs and preferences. But choice is not a meaningful option without easy access to the information and knowledge which helps navigate towards informed decisions. Systems designed to give cash directly to families to pay for their own social care are known variably as direct payment, direct funding, direct purchasing and self-directed care. Despite the variety in terminology, these all refer to the same basic concept: using market-like arrangements within publicly-funded systems to support eligible individuals in making choices on which care and support they prefer, and who or what organization shall provide the care. From this fundamental principle, the ways in which purchase models can be organized vary significantly. To date, direct purchasing models have tended to emphasize services, giving less attention to other forms of support such as informal caregiving, home modifications, or technology and assistive devices.

There are number of ways in which direct purchasing can be organized. The UK is very active in implementing direct purchase solutions, with two basic approaches:

1) a person eligible for services may purchase community care using a direct payment from an overall sum of money allocated to them in the form of a personal budget; and,

2) a person may also ask the local authority to purchase certain services on their behalf using all or part of their personal budget allocation.

Within Ontario and Canada, the movement towards direct purchasing is growing but still relatively small in size and reach, with approximately 16 self-directed programs available in different provinces and federally (through the Veterans Independence Program). Ontario has implemented the “Passport” program for adults with developmental challenges, and direct funding for some persons with physical disabilities. Similar innovations have been implemented in Ontario for persons with physical disabilities, and have been proposed for the “Caring About Caregivers” strategy (developed in consultation with Ontario’s Ministry of Health and Long-Term Care over the past two years). Less comprehensively explored is the use of the tax system to create an income stream which could then be used for a range of support needs. Regardless of the approach used, the critical determinant is the size of the personal budget or size of the credit – that is – are the available funds sufficient to meet?
Pilot programs which model alternative approaches to funding may be multi-ministerial collaborations, involving different ministries (e.g. Finance; Child and Youth Services; Community and Social Services; Health and Long-Term Care; Health Promotion and Sport) and different levels of government (municipal; provincial; federal).

**Strategic Option – Strengthening Options for Personal Choice**

Building a structure for choice requires shifts in both the public sector and the private market, as well as those areas where the two spheres of economic activity meet (e.g. the Assistive Devices Program). The concept of building for choice is simple and intuitive, though it is complex in design, policy and allocation. But solid research from a host of provincial, national and international jurisdictions is laying the groundwork on how to implement and manage direct purchasing for social care.

- **The Legitimacy Platform** – establish a blue ribbon panel of private industry and public sector representatives, with links to academic research for economics and social care, as the public national and provincial voice for independence and choice
- **The Credibility Platform** – initiate research processes in the areas of social needs definition and economic modeling using:
  - dynamic micro-simulation approaches to generate credible, evidence-based cost estimates of health and social need (e.g. the UK’s Personal Social Services Research Unit is a source of almost two decades of this type of research experience)
  - identification of existing operational models for direct purchasing and tax-based approaches, encompassing social care, informal caregiving and mobility/communication technology
- **The Solution Platform**
  - Work with Ontario and federal governments to establish policy forums for reviewing the evidence and economics of choice-based systems (including funding and tax credit options)
  - Establish partnerships with social innovation leaders to stimulate ideas and approaches for creating a social economy of new “businesses” to ensure an open market with adequate choice

**Strategic Option – Innovation in System Navigation**

The appearance of choice without the information and knowledge to support it is an illusion, not a solution. Health care system users require easy access to information on funding options and purchase opportunities. Systems need to be created in such a way that the opportunity for choice does not simply become a shift in responsibility — further burdening persons with a neurological condition and their families/informal caregivers. (For example, about ten percent of caregivers in the UK responded that direct purchasing was merely making them do the work traditionally done by public services). Building and implementing system navigation tools through one-stop portals has
become a routine expectation in US private health benefit systems. Navigation tools such as Connect Your Care provide ready online access to health and wellness information, a full range of information regarding availability and choice in options, tools for comparing providers and medications and, in the case of Benefitfocus, a language translation system in a wide range of languages and dialects.

Alongside these corporate activities, user group driven system navigation is rapidly emerging to augment formal information with social knowledge. Networks are emerging such as “patients like me” with a wide range of groups participating, including Multiple Sclerosis, Parkinson’s Disease, Amyotrophic Lateral Sclerosis/Motor Neuron Disease, Primary Lateral Sclerosis, Progressive Muscular Atrophy, Progressive Supranuclear Palsy, Corticobasal Degeneration, Multiple System Atrophy, and Devic’s Neuromyelitis Optica.

- Work with social innovation partners to develop a business case and model for a System Navigation Portal using a care map approach. An easy system in which one enters information (e.g., neurological condition, age, gender, employment status) and that input returns knowledge on each medical and social aspect of the condition, provided in useful categories—e.g., medical care; employment and income support; housing options (such as renovation tax credit); independent living; facility living. This Portal could be part of the NeuroResponse system discussed earlier, and include the capacity for direct contact and face-to-face consultation.

- Establish with Accreditation Canada a process of accreditation for social care and technology providers to enhance the quality, legitimacy and credibility of service organizations and vendors. This accreditation would form a core requirement for inclusion on the System Navigation Portal.

System Design Element: Strengthening Community Support

For the past two decades initiatives to strengthen and integrate community systems of support have formed the basis of policy dialogue and action in the areas of seniors and long-term care services, mental health, children’s services. Front and centre in all these initiatives is the recognition that services are fragmented with few formal (or even informal) connections. In all these different human service sectors, the development and growth of organizations and services have arisen in an ad hoc fashion. The net result is a sometimes disjointed array of services across a wide range of functional supports such as medical care, rehabilitation, and basic daily living activities for significantly different populations. This fragmentation means that the policy framing issue is not simply about an insufficiency of supply, it is also the matter of how such supply is organized.

In the current environment, Local Health Integration Networks (LHINs) are under great pressure to establish new transfer payment arrangements in a difficult economic environment. The fundamental issue is not simply the administrative burden of creating more agencies, but the reluctance to add to what is already well-recognized as a fragmented system of services.
From a systems perspective, the PRISMA model in Quebec provides an example of what is possible. PRISMA (meaning “Program of Research on Integration of Services for the Maintenance of Autonomy”) is a well-evaluated approach to integrating services for frail elderly persons within and between medical and social care requirements. While developed for a specific cohort, the design elements and practices of the model have received international attention and could be transferable to other specialized needs. In England, Integrated Neurological Services in Richmond is attracting attention for creating a community support service that substitutes disease focus for functional need and support requirements. It is in this context that the future of neurological specific community care must find a way to not just exist, but thrive.

At the same time, care and community support is divided not only by agency and diagnosis, but also by age and sector – divisions in policy and administration that create service crevices at important points in life transitions. The transition of young persons from youth-oriented services to adulthood is well-recognized as one such critical divide. Not only are we talking about the movement between two sectors – the professionalized perspective on the problem – but also the very process of a youth becoming a young adult with all the hope, fears and challenges this brings for any individual. Programs such as the Transition to Young Adulthood at Bloorview in Toronto represent an emergent service response, a response not yet more widely reflected in a systematic inter-ministerial approach to life transitions.

**Strategic Option – Shaping an Integrated System of Community Support**

Only a few health-funded community services currently have a specific neurological focus. Community support is dependent on more generalized approaches in senior, child/youth and physical challenges care. However, from a longer-term perspective, the present reluctance to create new health funding agreements does not preclude the growth of neuro-specific health funded agencies — but doing so will require organizations to establish a track record of service delivery and collaborative working partnerships.

- Work with the MoHLTC to establish neurological care as a provincial planning priority, through the development of an integrated system framework to guide local planning and funding

- Encourage the formation of an inter-ministerial task force between the Ministries of Health and Long-Term Care, Children and Youth Services, and Education on youth-to-adulthood for persons with a disability, and recommend the creation of local partnerships between LHINs and MCSS/MCYS regional offices for coordinated transition programs

- Undertake local epidemiological surveys to establish overall prevalence and potential “critical mass” of need to sustain neurological care services
Establish local partnerships with existing community support organizations, evolving neuro-specific knowledge and building neuro-sensitive capacity through current and future funding initiatives and allocations (e.g. Aging at Home)

Create a linked partnership between researchers and CCACs to facilitate the development of Community Care Maps and the creation of contracted “Service Bundles” for neurological care and support and palliative care

Explore the use of social enterprise models to create community organizations with specialized neurological expertise to compete for CCAC service contracts

Develop a strategy to promote volunteerism including the use of incentives (e.g. tuition off-sets) for application at the provincial and local levels

**Strategic Option – Caring for Caregivers**

Long recognized but not necessarily well-acknowledged is the critical role informal caregivers play in the support and well-being of persons with neurological conditions. Recently, Ontario’s Ministry of Health and Long-Term Care completed an LRSP process to identify future directions and policy ideas for explicitly supporting the role of informal caregivers. As such, there is a future-oriented strategic map that can assist the evolution of a comprehensive system of support for informal caregivers – including the expansion of who constitutes an informal caregiver beyond the parameters of immediate family members. System enhancing initiatives could be taken to strengthen the processes for recruitment, training and managing volunteers, further stimulating volunteerism among young people by offering tuition offsets, and increasing the ability of working adults to volunteer through employment-based programs. Flock Local is a compelling social innovation example which enables and supports voluntarism. Flock Local is an online service in the UK which emphasizes short-term matches and one-off activities from cleaning a garage to painting a shelter, making it easy for persons to get involved and make a quick difference in their community.

Engage in the planning and policy steps of the “Caring for Caregivers” strategy that includes:

- strengthening Ontario’s awareness of the informal caregiving role
- creating a formal process for caregiver assessment
- enhancing volunteerism for the 21st century
- a government-business dialogue for informal caregivers
- building benefits and employment protection for informal caregivers
- a provincial program with universal benefits and protection
System Design Element: Enhancing Social Inclusion — Income, Employment, and Housing

Social inclusion speaks to the complexity of how the social environment is connected and the opportunities, rights and entitlements that emerge through political and economic negotiation. There are innumerable indicators for measuring how well society is including persons with neurological conditions. Some measures are tangible (e.g. income, material circumstance), others are less so. In terms of tangible markers, most persons agree on certain fundamentals: a home, a job (or meaningful activity), and a decent income.

Yet, it is not just how or what is measured that is a critical factor, it is how the measurement is interpreted and determined to be either fair or unjust. The latter decision, determining injustice, ultimately drives the development of policy and action. Most stakeholders from the neurological community are in agreement that the current public expectations for social inclusion are set too low. A neurological condition is too often viewed in the wider social environment as inevitably meaning a lack of employment or low income — thus, such outcomes become acceptable in the public eye. To change this, there is a critical need to “shift the culture”. “Shifting the culture” means moving away from social beliefs and attitudes based on perceptions of difference, disability and charity to perceptions of value, contribution and rights. Shifting the culture is a prerequisite for improving our expectations.

Part of shifting the culture will require tangible changes to our infrastructure for how people with neurological conditions are treated, and the types of services and supports that are available to them. Progress on this piece may involve multi-sectoral task groups, with representatives and allies from within the many ministries, public organizations, and private interests who are influential and/or responsible for current and future funding structures, housing arrangements and employment assistance programs.

Strategic Option – Raising the Bar on Income

Income is an essential component of well-being and is solidly reflected in empirical research as a determinant of health. Not only does income provide for the basic necessities of life including food and shelter, it further influences or drives other opportunities to connect with and engage in society: from transportation to social activities and recreation to the clothes necessary to present oneself in society with a sense of pride and esteem. The shift in some policy discourse has moved beyond the word “poverty” to “social exclusion” for the very reason that a lack of income almost inevitably leads to profound disconnection and disengagement.

Current income protection policy in Canada and Ontario is viewed by many to be inadequate, although there is no consensus on “how much is enough?”. Continued efforts to reform income protection have yet to adequately deal with barriers and conflicts built into the criteria and processes.
that govern distribution. There are a number of reports which articulate the barriers to regular or part-time employment created by the rules of social assistance. These barriers include reform initiatives that inadequately recognize family or social circumstances, and a lack of recognition of the economic research which points out that a frequent determinant of low income is physical and/or cognitive impairment. Complicating the latter barrier are the income assistance rules which often introduce restrictions or claw-backs.

Ensuring an adequate income is not charity – it shifts from the tangible of materialism to the intangible of social inclusion and cohesion. Countries such as Sweden and Finland have established comparatively stronger income transfer policies than countries such as Canada, the US and the UK, and yet these Nordic countries also demonstrate significantly higher rates of employment for disabled persons. With this social recognition, policies also focus on initiatives that encourage employment and discourage claw-backs. From this perspective, decent income appears to be an act of inclusion that carries over into wider society, moving the yardstick from charity to social citizenship.

Social exclusion is not the exclusive preserve of persons with a neurological condition. Many vulnerable persons share the same poor outcomes for similar reasons. Logically, sharing of a problem or challenge is strongly indicative of an opportunity to share in solutions. Action on social barriers and policy is not well executed if voices for change are fragmented or even in competition. The strategic implication for policy is that new lateral partnerships are required in a variety of social domains to push forward on the tangible indicators of social inclusion.

- Create a bold partnership with other disability groups to influence current social assistance reviews, and further establish a collaborative initiative for the investigation of income streams that cut across payment mechanisms (e.g. ODSP, insurance, pension) within federal and provincial governments and the private sector

- Work to improve Disability Tax Credits and Registered Disability Savings Plan so that each is available and beneficial for persons with lower incomes and less room for savings – link improvements with an online decision support resource (e.g. modeled on the Canadian Retirement Income Calculator)

**Strategic Option – Employment for All**

Promoting the need for income support is not simply a matter of social assistance policies and programs. Many persons with a neurological condition are willing and able to participate in the economy through various forms of employment. Not only does employment provide a potential source of income to enhance an individual’s and family’s access to material goods, it also represents for most a valued role in society and source of self-esteem and self-worth.
“Shifting the culture” in the labour market and working conditions is similar in magnitude to shifting income policy. It is a complex undertaking—requiring a fine balance of policies, incentives and initiatives that support shifts in societal attitudes through pragmatic instrumental “tools”. Most agree that simply relying on the altruistic attitudes of employers will be an insufficient condition to “push” this form of social inclusion. Instead, there is a need to create “pull” factors — making the economic case that many persons with a neurological condition possess experience, skills and education of significant workplace value. In the face of a possibly decreasing labour supply, there is a positive trend towards embracing technological means which make work conditions and processes flexible. If utilized, this trend could re-open doors currently closed to those employees who require modified employment environments/conditions.

Social innovation can foster small solutions with potentially large returns, e.g. creating socially innovative employment support programs that assist in the recruiting of employers, while offering ongoing support to employee and employer alike. A UK example of this type of solution is an online job bank that enables employers to post short-term work availability, and in return, persons with limitations offer their time on a basis that meets their particular needs.

- Help re-shape the existing labour market through the creation and implementation of a business case for the establishment of a supported employment service by:
  1. developing the service model;
  2. researching the various sources of income assistance (e.g. ODSP, insurance, and pensions) to identify and demonstrate the “social return” of reduced unemployment;
  3. work with specific income sources (public and private) to shape flexible criteria that accommodates a range of employment options.

- Work to expand the supply of employment opportunities with social innovation groups through the development of a strategic plan for social enterprise business models and sources of social venture capital

- Advocate for the creation of a publicly funded “employee benefit” program for persons with a neurological condition, to offset private employer requirements

- Develop and promote legislative protection regarding the use of restrictions on employer health screening programs

- Work to accelerate the implementation of the Accessibility for Ontarians with Disabilities Act (AODA) and its corresponding Accessibility Standards, with particular focus in this area on the development of Ontario’s Accessible Employment Standard
**Strategic Option – Housing for All**

For most people, housing is a judicious balance between affordability, location and basic needs shaped through preference. Despite all the constraints, economic and otherwise, placed on the housing decision, it remains a personal choice. Eliminating all constraints on housing options for persons with a neurological condition is not a reasonable goal – few of us ever have that much control. However, the present barriers in terms of income and specific needs are such that the “circle of control” for persons with a neurological condition is often very small. Even more problematically, the issue is not simply deciding where to live, but an issue of ability and capacity to remain where one has already chosen to live, prior to the onset of the neurological condition.

There is no single pathway to housing, particularly when innovation in design and funding is required. There are some examples of useful small actions such as Bank of America’s Low Income Housing Challenge in which University of California MBA students developed a solar- and wind-powered urban “oasis” for low-income housing. Some larger action (such as growing Canadian interest in Housing Trusts) is underway to develop a range of housing options with a central role being the securing and allocation of multi-layered public, private and charitable funding. Housing has always been a field of intense innovation and a new wave is emergent. Housing Works in the US is operating a number of social enterprises, including a coffee shop, thrift stores, an online auction website, and a catering business to generate $13 million for the housing budget. Similarly, Common Ground is a not-for-profit housing development and management organization running a Ben and Jerry’s “Partnership” to fund housing objectives.

Expanding the “circle of control” requires a flexible housing strategy, with options that distinguish between the core elements of affordability, location and health/social need, and adaptability to changing needs over the trajectory of the neurological condition.

- Promote the development of new flexible forms of housing in the form of a system plan which considers:
  
  - Adequate supply of integrated community support, enabling one to remain in their current home rather than having to move to obtain health/social care
  
  - A universal system of tax credits and/or funding for the purposes of home modification and assistive devices
  
  - Social enterprise to innovate in different forms of designed housing (e.g., independent living, congregate, respite and hospice) as well as developing and exploiting new housing business models and approaches to generating capital and revenue, reducing reliance on government sources
• Unique partnerships with universities – architecture, human design etc – to create innovative housing designs at low-cost/no cost

• Age appropriate environments for those seeking or requiring more inclusive facility care

• Work with the Ministry of Municipal Affairs and Housing through the development and implementation of Ontario’s Long-Term Affordable Housing Strategy, as well as with housing developers and supportive housing providers to develop accessible, affordable housing and supportive housing for people with neurological conditions

System Design Element: Enhancing Social Inclusion — Social Connections and Participation

A deeper form of social exclusion underlies the empirical indicators of social inclusion — from the simple mark of having a friend or friends to the mobility of enjoying one’s neighborhood to the high level connections of meaningful citizenship and participation in a liberal democracy. Certainly these objectives can be measured in terms of frequency or rates, though it is not difficult to understand that the quantitative count of friends hardly begins to explain the profound psychosocial impact of what many of us take for granted in our lives.

One outcome of this system design element may be the extension and expansion of those technologies which facilitate new forms and means of social connection — which allow socialization to happen through channels that work around and with physical and mental barriers. Online socializing hubs such as those described in “Creating Social Networks” represent the first forays in using technical resources to connect people despite geographic and physical boundaries. By working within this space, the charities of NHCC have an opportunity to participate in what is becoming the “new normal” for many of their constituents, as well as a chance to push those technologies and resources forward to the “next normal” – expanding service and resource delivery to take advantage of additional low and high tech options.

Strategic Option – Social Participation Campaign

Shifting the culture is once again a dominant feature of this future. It starts with one of the key foundations of opportunity and social mobility and inclusion in our society — education — and then reaches across some of the core elements of what enables people to connect with and feel connected to the larger environment. Such a shift moves beyond the constraints of reducing social stigma, and reaches forward to the promotion of a social participation that is robustly grounded in social value and the rights of citizenship.
Join forces and secure funding for a pan-Canadian campaign with linkages to provincial and local groups, promoting the right of persons with a neurological condition to fully participate in society, and articulating the benefits society gains from social inclusion.

**Strategic Option – Partnerships for Healthy Cities**

How we design our built environment poses significant challenges and barriers – from the density and mix of residential and commercial, to the layout of public space and the availability of transportation. The built environment is a significant determinant of disability. Paying attention to the requirements of persons with neurological conditions in municipal planning is a signal of inclusion.

Early in the 21st century there is a marked shift towards planning and design principles that enhance the lived physical experience: a trend towards shrinking and mixing urban space with attention paid to the needs of people versus cars. The final outcomes of this trend remain uncertain, but even if we only assume that this trend will continue, there is a disturbing pattern in which private market prices are dictating who can take advantage of the friendlier neighbourhood aspects of the new lived environments. The potential that re-generated neighbourhoods are economically inaccessible and lack a public policy of inclusion, confine those with neurological conditions to far less accessible areas.

Establishing the basis for “healthy” and “enabling” local environments requires an intersection between health systems and local planning systems. Innovative collaborative partnerships such as the **NHS London Healthy Urban Development Unit (UK)** model these intersections. Established in 2004, this initiative formed “to promote health improvement and the narrowing of health inequalities in London through pursuing the alignment of health and planning strategies and by facilitating effective engagement between the health and planning sectors”.

Public policy does not arise in a vacuum: it typically reflects a configuration of agreement amongst political, business and social interests. The “healthy city” and related movements are citizen-driven actions that for over twenty years have attempted to reconfigure agreements on design and development. Certainly these movements have not been neglectful of the special needs of persons with physical and/or cognitive impairments. However, there remains the task of translating high level visions of a “healthy city” into specific municipal regulations and planning decisions. Action does not stop with a vision: it requires involvement in the operations of municipalities and regions, and the political negotiations underlying these regulations and decisions.

- Create partnerships with existing citizen coalitions and groups to align physical design requirements with wider urban advocacy by:

  1. mapping the existing coalitions and groups that function at municipal and neighbourhood levels;
2) mapping existing citizen participation opportunities within municipal government planning processes;

3) developing a balanced strategy of partnering with such groups and processes;

4) articulating a set of recommendations that can influence official plan development; municipal zoning and development approval (e.g. negotiating trade-offs between density and neighbourhood benefits with specially designed affordable units) and accessible transportation options

5) promoting the adoption of and compliance with the accessibility standards outlined in the Accessibility for Ontarians with Disabilities Act (AODA) as a basic common denominator of healthy cities’ agendas

Encourage partnerships between municipal/regional planning departments and LHINs to facilitate the planning of “healthy” social infrastructures

**Strategic Option – Creating Social Networks**

Over the course of LRSP stakeholder discussions, there was much debate as to the merits and pitfalls of technology as a socially connecting process. To some extent, this debate reflects generational attitudes and experiences towards social networking as an anti-social experience. However, being overly engrossed in debates over the pros and cons of technology may lead to missing out on what is already occurring. Recent empirical research indicates that older Canadians are the fastest growing group of users of internet technology, while socially connecting websites such as patientslikeme.com and teenconnector.ca (a social network site for children and youth with cancer) continue to proliferate.

Perhaps the important question is not “should technology become a prevalent form of social networking and connection” but rather recognizing that there is an emergent trend saying “yes”. A more productive question may be “how can we add value to this trend?” The most obvious value gain is creating a safe, reliable and protected social platform in what is currently an open and unprotected movement. Privacy of information, exposure to unfair marketing, and misinformation all present risks in the current “wild west” environment. In the case of teenconnector.ca, the initial phase of implementation is funded by a pharmaceutical company and operated by the Childhood Cancer Foundation. A moderated online community with news feeds, profile pages and digital walls can be managed to the benefit of users rather than private interests. In the UK, social innovators have created Shift.ms, a community for young people affected by Multiple Sclerosis to interact and provide mutual support. Overall, there are good reasons to anticipate that the trend towards online social networking will continue and accelerate — but the window for helping to shape and influence this trend is open.
Develop and implement business cases for social networks platforms for persons with neurological conditions which are sensitive to population differences – preferably linked with the previously described NeuroResponse network.

**Strategic Option – Promoting Health for Persons with a Neurological Condition**

Confining persons with a neurological condition to electronic communication is clearly an insufficient basis for social inclusion and health. Broadening the ways in which people with impairments access social resources to promote and maintain their health is a social determinant requiring substantive thought and action. Most people are familiar with the World Health Organization’s definition of health as “more than the absence of disease”, but such recognition is in need of expansion — that health promotion does not simply stop in the presence of disease or disorder. Over the past five years, Ontario has taken a positive lead in exploring ways of involving schools and social recreational centres to more effectively address obesity through physical activity and positive social interaction. From this flurry of activity, innovative approaches of reaching out and engaging low socio-economic populations with limited access to such resources have been developed and implemented.

What has not been recognized in this or other excellent health promotion work is the in/accessibility of social resources for those with a physical and/or cognitive impairment: a social inclusion gap in health promotion.

- Encourage the Ministry of Health Promotion and Sport to engage in an innovative, globally leading process of inter-Ministerial planning for a “Health Promotion Plan for Persons with a Disability”
Stream of Work: Social Innovation
One of the challenges of neurological disorders is that we know so little about how to prevent them. Furthermore, as a society, we have concentrated a disproportionate share of publicly financed resources on diagnosis with an imbalance of attention to the supports needed for daily living, education, meaningful work, social participation in the community and personal mobility.

Social innovation strategies represent an opportunity to change the questions we ask about these intractable problems, and to imagine a whole series of supports, partnerships and explorations which challenge a too-often depressing status quo.

A commitment to social innovation will invite us to bring business, government and the non-profit sector together to consider opportunities for social change, opportunities to develop new knowledge, and opportunities to address the pent-up demand for alternatives – in education, in social support, in financing, in employment, in the application of technology – to name but a few.
System Design Element: Fostering Technology and Research

For many, technology is often seen to be what is new, or in 2010 simply what is digital, electronic or wireless. Yet the advent of the computer and word processing does not change the fact that a typewriter is a technological device (as is the pen or pencil for that matter). Getting lost in the future can cause us to lose sight of the fundamental purpose of “technology” – the potential to aid and assist us in our daily lives, with the equal potential to ultimately transform our daily lives in uncertain ways.

For many participants in the LRSP consultation sessions, technology and the pace of technological change and innovation was viewed as persistent in the face of all the possible social, political and economic drivers that will affect us over the next 25+ years. Such change was seen as transforming the experience of persons with neurological conditions, ranging from the possibility of more effective and/or tailored treatments (or even cures) to the availability and power of communication and assistive devices. This does not of course imply that one can easily predict types and forms of technology, but rather that such change will almost certainly occur and thereby open up opportunities and/or create threats.

There is a need to stimulate advances in how technology can be developed, and commercialized, for the advance of social good. In the UK, the Foundation of Assistive Technology was established over ten years ago as a charitable organization spanning the domains of private innovative and public policy in assistive technology. Dedicated to the development of technology and led by the needs of the disabled, the Foundation brings together people who use technology (researchers, developers, manufacturers and service providers) in a partnership framework known as the AT Forum. The Foundation further tracks and reports to parliament on government-funded research activities. In Sweden, the Swedish Handicap Institute is a jointly funded organization with contributions from the Ministry of Health and Social Affairs, the Federation of Swedish County Councils and the Swedish Association of Local Authorities (the latter groups in recognition of the critical role of municipalities in funding and allocation). The function of the Institute is to advise on assistive devices and more recently has branched into building design standards for architects and builders as well as newly emerging communication and mobility technologies.

At the “smaller” end of the continuum, social innovation is once again evolving enterprising ways of using technology and design to enable persons with a disability in their daily lives. Enabled by Design was created in 2003 by a young woman with MS. Frustrated by assistive devices that made her home “look more and more like a hospital”, she created a social enterprise which provides advice on and encouragement of new ideas on how devices can be more friendly to the touch and to the eye. This is a compelling example of how “bench” science and research can be made accessible and useful in the hands of the user in an accelerated manner and through a customized process.
In previous sections, we have discussed some of the ways technology is improving or can improve the lives of persons with a neurological condition: communication technology creates channels for medical knowledge or social interaction which is not bound by geography; monitoring devices similarly can reduce or eliminate physical and geographic limitations; mobility devices can already re-open a world that has been closed, transforming a disability into renewed ability.

Concurrent with this fostering of accessible technology is the continued need to support and strengthen basic Ontario-based clinical and applied research on neurological conditions. Improving the quality of life for Ontarians’ living with neurological conditions is linked to building on Ontario as a centre for research, technology and innovation. Advancements in neurological research and technical assistive devices can build on the work of Ontario innovation centres either established (MaRS) or burgeoning (Ontario Brain Institute). Partnerships with these organizations may be advantageous in advancing and accessing leading neurological research and support technologies.

**Strategic Option – Creating a System of Technology**

The near consensus on the inevitability of technological development and adoption shifts the question from “should technology evolve and transform” to “what are the appropriate processes, incentives and equitable means of allocation”? That is, to better manage the fundamental purpose of technology in human lives: enabling and helping. The suggestions made in the “Caring About Caregivers” strategy are also applicable here:

- Promote the creation of a research strategy and organizational mechanisms for health enabling technology in a way that generates economic benefits for Ontario (e.g. Ontario Brain Institute as announced by the province in November 2010) and positively influences the development of technology that can improve the lives of persons with a neurological condition.

- Promote the creation of an evaluation infrastructure for assessing public funding of new technology and remain an active participant in the operational review process. A comprehensive review of existing government structures and processes (e.g. Medical Advisory Secretariat; Assistive Devices Program) should be enacted to integrate and modernize mandates, criteria and funding mechanisms to more efficiently and effectively foster technology development and adoption.

- Work with government on improvements to pharmaceutical formulary and policies governing coverage and accessibility.

**Strategic Option – Advancing a Research Strategy for the Brain**

In 2009, the NHCC was successful in engaging the federal government to invest $15 million in research funding to study the prevalence and impact of neurological conditions in Canada. This research will investigate: the incidence and prevalence of neurological conditions; risk factors for developing neurological conditions and for progression; the impact of neurological conditions on
individuals, families, caregivers and communities; and health services. Work on rolling out these investments is well underway and should generate critical information and attention over the coming years. The NHCC has also proposed the development of a national brain strategy and it appears this idea may have some interest with stakeholders at the federal level.

- Work towards the establishment of a new series of research and applied practice chairs in the areas of neuro-psychiatry and integrated health system development

- Maintain and further promote an active role by the provincial and federal governments to undertake research and, most critically, develop a “brain strategy” that fosters the coordination of neurological research and public policy which supports individuals with neurological disorders.

**System Design Element: Building a Neuro Partnership**

The NHCC is an innovative partnership of neurological charities in Ontario. During the consultation sessions some discussions considered the future role options of such a coalition in supporting the needs of individuals with neurological conditions. This resulted in the most varied responses in the LRSP process. This variety could be partly explained by the newness of the coalition itself as well as varying understandings of the role and functions of each coalition partner. At the same time, a cohesive neurological strategy would in itself enable members to determine new ways of working together. In other words, with no common consensus on direction it is difficult to determine the means of achieving this direction.

One area of strong consensus among most stakeholders was the need for the diversity of neurological conditions to have increased awareness in the minds of Ontarians. Most stakeholders agreed that given the “information pollution” that is intensifying through all the various forms of media (old and new), there would be great advantage in creating a compelling brand image for social marketing and fundraising purposes, to the shared benefit of all NHCC organizations. The most frequent comparison of how to achieve this “branding” was in relation to cancer and the heart. The future determinants of fundraising success in the face of increased competition (including the movement of large American charities into the Canadian/Ontario charitable sector) would seem to revolve around finding a way of building size and focusing profile.

A smaller number of stakeholders felt there could be other benefits of meaningful collaboration that would not imperil the autonomy of partners, but still accrue financial benefits and operational gains. For example, integrating back office functions would not affect the independent voice and knowledge of less prevalent conditions and smaller organizations, but would improve overall organizational effectiveness and efficiency.
Strategic Option – A Sustainable Partnership for the Future

Generative relationships and imaginative partnerships across economic sectors can strengthen the development of an Ontario Brain Strategy and help it move forward iteratively towards the comprehensive strategy required by so many Ontarians.

- In the development of an Ontario Brain Strategy, identify and sustain new ways of working together to implement the plan and work effectively with other partners (e.g. government and business) in policy making and program development.

- Create a provincial roundtable on neurological health with public, non-profit and private sector leadership, with a mandate to stimulate innovation and new funding sources in areas of detection, education, care, employment and technology.
Stream of Work: Education for All
As in so many areas of public policy work, the mantra of “begin as you intend to continue” comes to mind. Today, the majority of school boards across Ontario struggle with the timely identification and resourcing of the learning needs of children and youth with neurological disorders (see the NHCC’s White Paper – “Ontario Brain Strategy: Realizing ‘Education for All’”).

There are exceptions – and in the parlance of social deviance and system innovation, these exceptions to the majority’s struggle need to be examined for the insights and hope that they hold. Children and youth who are supported fully in their education are on a radically different life trajectory than those who are identified as needing additional resources but not adequately included in the mainstream of education.
**System Design Element: Enhancing Social Inclusion — Education**

A strategy to improve social inclusion for Ontarians living with neurological conditions must include evaluation and redressment of gaps in the education system. This is necessary both for young Ontarians living with neurological conditions, and as a means for shifting culture away from stigmatizing these conditions, and fostering understanding. Finding and involving partners and expertise from the Ministry of Education, boards of education, teachers and parents at all levels will be necessary to achieve positive outcomes.

**Strategic Option – Education for All**

Education is the foundation of opportunity and social mobility in modern societies. This is no less true, relevant and applicable for those with neurological challenges. However, there are many challenges in moving from a well-intended statement of principle to the pathways and mechanisms required to enact the principle in real and meaningful ways. Currently, provincial education policy for children and youth with special needs is largely driven by funding categories that are linked to specific recognized conditions or disorders. Access and opportunity is divided into decisions of whether a specific learning challenge is funded or not – decisions that ultimately result in significant inequities in opportunity.

Shifting away from a piece-by-piece approach requires wide action rooted in knowledge and policy. In Europe, the European Agency for Development in Special Needs Education is conducting research and developing policy guidance ranging from best practices in inclusive classroom practices to individual transition plans that support the movement from education to employment. In the UK, the Lamb Inquiry recently completed a comprehensive holistic review of special education needs, funding and assessment to enhance parental confidence and improve opportunities for students.

The question remains how to effectively insert specialized need into a “mass production” process. Research in a number of different areas of health and social need point towards the need for a “whole school” process and adoption of new learning processes and technology. Once again, the agenda for change is large and complex. It requires new forms of partnership and connecting relationships to develop, test and implement innovative ideas and methods.

- Establish a partnership with the Canada Research Chair in Special Education and Adaptive Technology, OISE, and or Canadian Education Association for a research agenda leading to “whole school, whole child” pedagogical approaches and socially innovative solutions to reconfigure learning experiences, online opportunities and classroom design and processes, helping to inform future policies and funding in education systems.
Conclusion

Neurological conditions have profound effects on quality of life. Such effects can cut across aspects of what most people consider the necessities of a good life: friendships, family relationships, income, employment, housing and social participation. From the simple act of walking the dog to the modern cognitive need to multi-task, the onset of a neurological condition can lead to the loss of what many take for granted in their lives. Not only can a neurological condition lead to the need for complex medical care or expensive pharmaceuticals, it also has the potential to dramatically alter expectations. The expectations of a senior for a full and flourishing retirement. The expectations of a parent for their child to find their place in society. It is not inevitable that these expectations will change but, given the current systems of health care and social policy, it is likely.

Although current epidemiology is incomplete, we are sufficiently aware that a large number of Ontarians are dealing with a neurological condition. We are also confident that the number will grow with an aging population. What is less certain is how advanced treatment and interventions might progress in the coming years, as knowledge and technology rapidly advances in many areas of brain research. Also open to question, and change, is how well the social environment evolves and adapts to find new and positive solutions to the human challenges such conditions present.

The LRSP process and its identification of the building blocks of an Ontario Brain Strategy are an attempt to understand how change might evolve and, more importantly, to identify the ways and means by which proactive approaches and solutions can be implemented. While much of the future is uncertain and hard to predict, concrete policy and action can create a greater degree of certainty. This report outlines a set of plausible policy implications for enhancing health and human services across multiple social domains, to improve the quality of life for persons with neurological conditions. The implications necessitate innovative ways of thinking about solutions and equally innovative ways of working with a wide range of partners. Such policy implications consider how future trends can be used to enhance opportunities in the face of economic, political and social uncertainty in the coming years. Moving from these policy implications, a broad basis of dialogue and the shared exploration of a preferred future can evolve.

Being largely ignored, under-funded and misunderstood by the majority of the health community can be devastating — and being stigmatized for neurological conditions that are so prevalent in our own extended families, neighbourhoods and communities is beyond comprehension. Neurological disease is a very personal journey lived out in every community — and the creation of a national brain strategy in Canada will be the test and measure of our maturity as a country that prides itself on both its compassion and its knowledge-based economy.