

# NPHSNC: USE AND GAPS IN HEALTH AND COMMUNITY-BASED SERVICES FOR NEUROLOGICAL POPULATIONS - A SYSTEMS ANALYSIS

---

**Dr. Susan Jaglal,**

Principal Investigator, Professor, Department of Physical Therapy, Toronto Rehabilitation Institute Chair at the University of Toronto

May 29, 2013



Funding for this project has been made possible through a grant from the Public Health Agency of Canada

# Research Team members

## Investigators:

- **Dr. Susan Jaglal**, Principal Investigator, Professor, Department of Physical Therapy, Toronto Rehabilitation Institute Chair at the University of Toronto
- **Dr. James Conklin**, Assistant Professor, Department of Applied Human Sciences, Concordia University
- **Dr. Sara Guilcher**, Physical Therapist and Post-Doctoral Fellow, St. Michael's Hospital, University of Toronto
- **Dr. Connie Marras**, Assistant Professor, Neurologist and Epidemiologist, Department of Medicine, University of Toronto
- **Ms. Sarah Munce**, Doctoral Candidate, Department of Health Policy, Management & Evaluation, University of Toronto
- **Dr. Tanya Packer**, Professor and Director of the School of Occupational Therapy, Department of Occupational Therapy, Dalhousie University
- **Dr. Richard Riopelle**, Professor, Department of Neurology and Neurosurgery, McGill University
- **Prof. Molly Verrier**, Associate Professor and Director of Distributed Rehabilitation Sciences Education, Graduate Department of Rehabilitation Sciences, University of Toronto
- **Dr. Joan Versnel**, Assistant Professor, Department of Occupational Therapy, Dalhousie University

## Research Staff:

### *Toronto-based Site*

**Mr. Tarik Bereket**, Research Coordinator

**Ms. Mae Kwan**, Research Assistant

**Ms. Atiya Hemraj**, Health Studies Student

### *Montreal-based Site*

**Ms. Emma Legault**, Research Assistant

### *Halifax-based Site*

**Ms. Jennifer Lochbihler**, Research Assistant



# Stakeholder Advisory Group (SAG)

Conditions (n=16)	SAG Member (n=18)	Representation
All conditions	Gail Mores	Director of National and Provincial Programs, March of Dimes Canada
ALS	Eleanor Leggat	Vice-President, Support Services, Amyotrophic Lateral Sclerosis Society of Ontario
Alzheimer's	Jacque Micallef	Public Policy and Chapter Relations Analyst, Alzheimer Society of Ontario
Acquired Brain Injury	Harry Zarins	Executive Director, Brain Injury Association of Canada
Brain Tumour	Maureen Daniels	Past Chair, Canadian Alliance of Brain Tumour Organizations
Cerebral Palsy	Gordana Skrba	Administration and Executive Assistant, Ontario Federation for Cerebral Palsy
Dystonia	Diane Gillespie	Executive Director, Dystonia Medical Research Foundation Canada
Epilepsy	Heather Walker	Caregiver/Parent of two epileptic children, Epilepsy Ontario
	Melanie Jeffrey	PhD Student Volunteer/ Epileptic, Epilepsy Ontario
Huntington's	Bev Heim-Myers	CEO & Executive Director, Huntington Society of Canada
Hydrocephalus	Joan Booth	Executive Director, Spina Bifida & Hydrocephalus Association of Ontario
MS	Sylvia Leonard	VP, Programs and Services, National Office, MS Society of Canada
Muscular Dystrophy	Marla Spiegel	National Director, Research, Programs & Services, Muscular Dystrophy Canada
Parkinson's	Debbie Davis	CEO, Parkinson Society Central & Northern Ontario
Rett Syndrome	Terry Boyd	President, Parent of daughter with Rett, living w/ MS Ontario Rett Syndrome Association
SCI	Vanessa Noonan	Director, Translational Research Program, Rick Hansen Institute (BC)
Spina Bifida	Joan Booth	Executive Director, Spina Bifida & Hydrocephalus Association of Ontario
Tourette Syndrome	Lynn McLarnon	Executive Director, Tourette Syndrome Foundation of Canada
	Rosie Wartecker	Volunteer/Past Tourette Foundation Chair, Tourette Syndrome Foundation of Canada

# Objectives of the Webinar:

- Present the study results on **health and community-based service needs and gaps** for neurological populations in the Canadian context
  - *from the **perspective of service providers***
- Introduce the newly developed “Chronic Care Model for Neurological Conditions” (CCM-NC)
- Present **recommendations** to help policy-makers, health charities and service providers plan programs



# Key Informant Interviews: Sampling

- Efforts were made to sample from roughly:
  - 40%** Health Care Professionals (**HCPs**),
  - 40%** Non-Health Care Professionals (**NHCPs**), and
  - 20%** Policy Makers (**PMs**) across the country.

***n= 334 invitations sent***
- As of October 25, 2012:
  - 39%** (n=70) HCPs,
  - 47%** (n=85) NHCPs,
  - 14%** (n=25) PMs

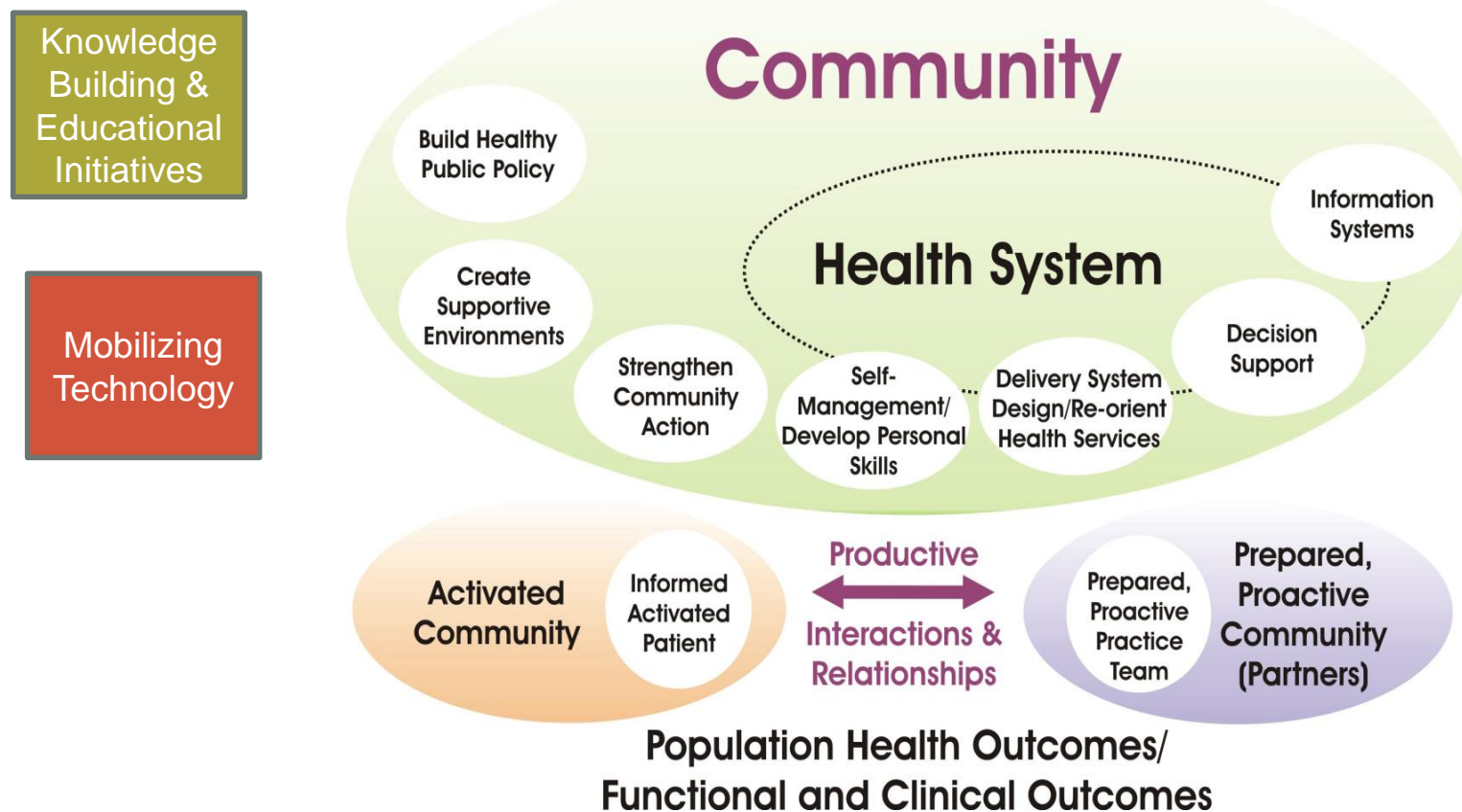
**...180/180 interviewed.**



	Key Informant Interviews			
Neurological Condition	Invitations sent	Non-response	Refusals	Completed Interview
ABI	17	1	4	12
ALS	15	8	1	6
Alzheimer's	20	1	3	16
Brain Tumor	28	16	5	7
Cerebral Palsy	15	3	3	9
Dystonia	18	9	3	6
Epilepsy	17	5	3	9
Huntington's	13	4	0	9
Hydrocephalus	10	6	0	4
MS	15	1	5	9
Muscular Dystrophy	21	4	2	15
Parkinson's	13	2	2	9
Spina Bifida	12	3	4	5
SCI	16	6	1	9
Rett Syndrome	22	2	7	13
Tourette's	11	2	2	7
GENERAL	71	13	23	35
TOTAL (n)	334	89	69	180
%		26%	20%	54%

# Analysis: Expanded Chronic Care Model

(Barr et al., 2003)



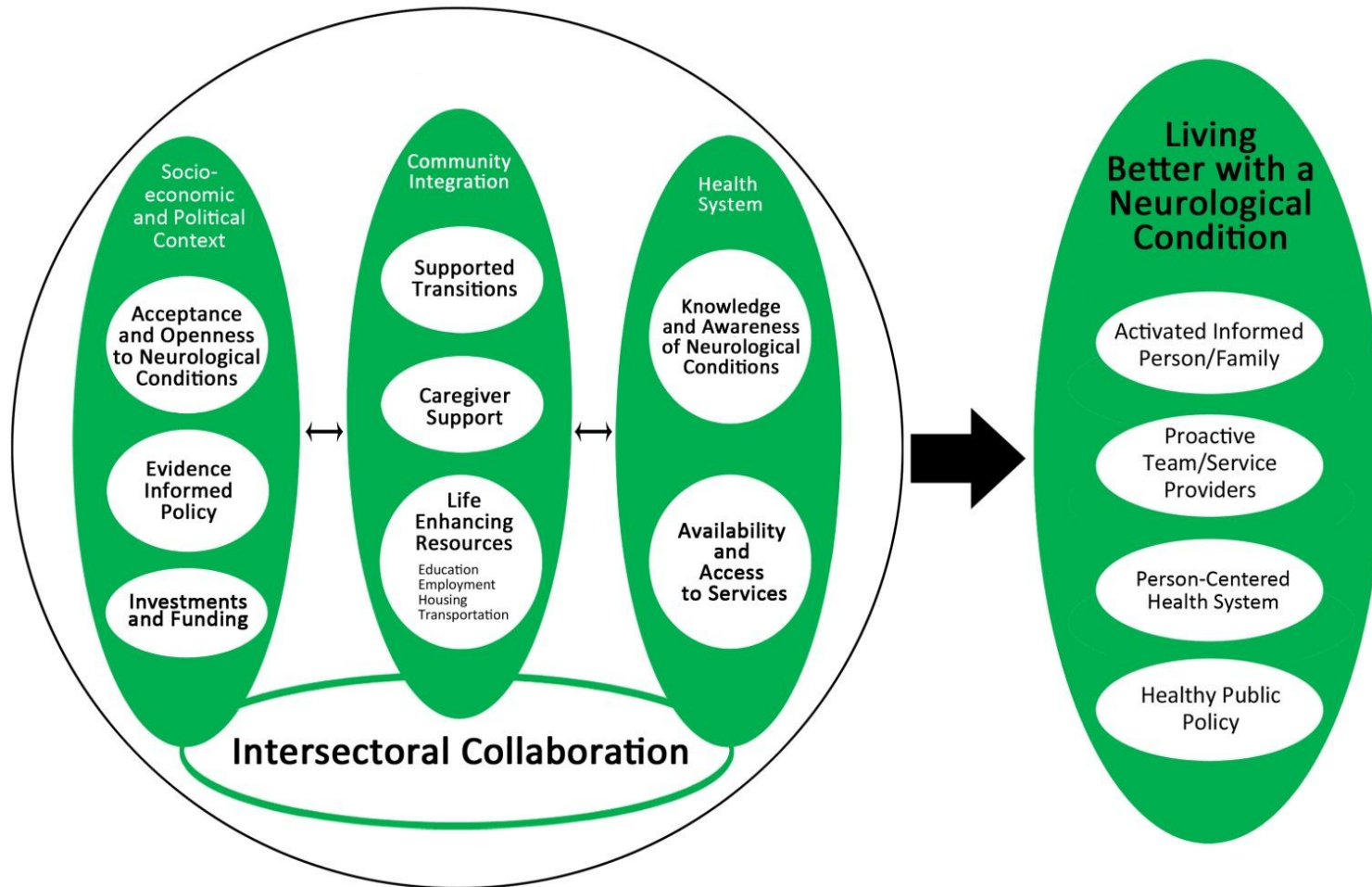
# Analysis

- Noted considerable overlap in themes across the categories
- Further analysis to identify patterns in the data for needs and gaps
- Developed a Chronic Care Model for Neurological Conditions (CCM-NC)
- Developed list of action-oriented [recommendations](#)



# Needs and Gaps

## Chronic Care Model for Neurological Conditions (CCM-NC)



# Socioeconomic and Political Context

## 1) Acceptance and openness to neurological conditions:

- Need to change mindsets to reduce stigma and marginalization
- Among those with NC reduce feelings of exclusion and isolation, embarrassment and reluctance to self-identify

## 2) Evidence-informed policy:

- Gaps in current policies and lack of availability of policies that address the needs of persons with NCs
- Need policies for funding to be reflective and supportive of persons with NCs, needs-based rather than condition specific and inclusive of lesser known neurological conditions
- Need to improve awareness and knowledge about available policies among service providers
- Need development of standardized policies

### 3) Investments and funding needs

- increase/improve health and community-based services and programs e.g. telehealth, medical and equipment programs, mental health programs, homecare services, caregiver support and transportation
- supports for training staff and caregivers to increase human resource capacity
- consistency in funding for school aged children with NCs and flexibility with eligibility criteria
- reduce inequities between workplace safety and insurance board, private and public insurance coverage
- reduce private insurance discriminatory practices

# Community Integration

## 4) Supported Transitions

- Need transitions to be a positive experience
- Need continuity of care within and between sectors
- Need access to services between acute, rehabilitation and community settings
- Need connectivity of information and services and inclusion of family doctors
- Need support for post-secondary education and employment
- For those transitioning to long-term care need overall support, case coordination and protocols

## 5) Caregiver Support Needs

- support to enable caregivers to “just be a parent”
- training and education for their supportive role
- help them to cope with behavioural challenges, promote autonomy and empowerment of persons with a NC
- support to navigate the health care system
- help with completing government forms
- support services
  - home support services,
  - respite care options for both the caregiver and the care recipient,
  - peer support

## 6) Life Enhancing Resources

- **Education system**
  - accommodate students with NCs
  - educate teachers and staff about the impact of NCs on students
  - increase funding for classroom supports
- **Employment**
  - provide meaningful and appropriate employment opportunities for both obtaining work and returning to work
  - reduce discriminatory hiring practices
- **Housing**
  - appropriate, affordable, accessible, safe and adaptive housing
  - age specific housing for younger persons with NCs
- **Transportation**
  - available and accessible transportation to get to medical appointments and to participate in social activities outside of the home

# Health System

## 7) Knowledge and Awareness of Neurological Conditions

- Increase knowledge and awareness about NCs among service providers
  - etiology, prevention, management, and services and supports available in the community
  - acute behavioral disturbances
- Develop more comprehensive evidence-based practice guidelines and online resources including webinars, Wiki platforms, peer-support, and innovative application software from credible sources
- Self-management
  - Need knowledge and understanding about self-management
  - Self-management support for youths with NCs in directing their own care

## 8) Availability and Access to Services

- Increase multi-disciplinary clinics with team-based care
- Person-centred care for NCs which requires shifting emphasis from diagnosis to functional co-morbidities
- Need for integrative case planning and services and supports in the community to facilitate a smooth transition to long-term care admission
- Need for funding of new assistive technologies, and associated education, training and technical support for the equipment
- Need health and community-based services in rural areas



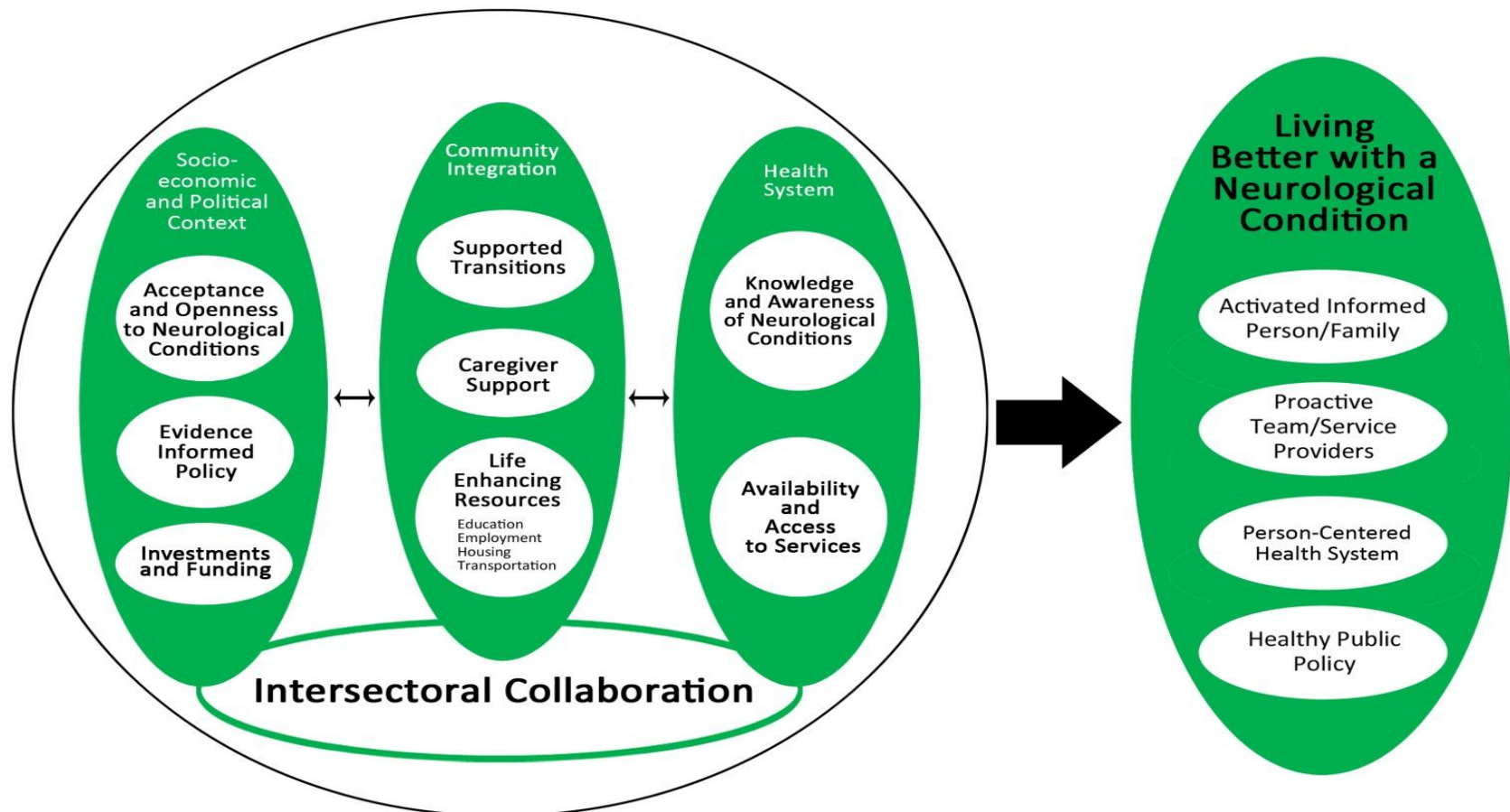
# Intersectoral Collaboration

**9) Intersectoral collaboration** is needed within and between the broader population setting (**Socio-economic and Political Context**), **Community** and the **Health System**:

- Need collaboration within and between health care and community-based settings
  - Need to share electronic health records
  - Align services across regions
- Need more resources for organizations to share knowledge and expertise about NCs
- Need better collaboration and cooperation between ministries of Health, Community and Social Services, and Education and service providers

# ACTION ORIENTED RECOMMENDATIONS

## Chronic Care Model for Neurological Conditions (CCM-NC)



# ACTIVATED INFORMED PERSON / FAMILY

## **SUPPORTED TRANSITIONS:**

- Provide supports to encourage youths in directing their own care

## **CAREGIVER SUPPORT:**

- Improve self-management support for Persons with NCs and caregivers
- Increase peer support opportunities for Persons with NCs and caregivers

## **AVAILABILITY and ACCESS to SERVICES:**

- Educate Persons with NCs and caregivers about available technology and provide trialing of technology prior to purchasing.
- Provide technical support for assistive devices, equipment, help lines etc.

## **INTERSECTORAL COLLABORATION:**

- Include Persons with NCs and caregivers as part of the care team

# PROACTIVE TEAM / SERVICE PROVIDERS

## **SUPPORTED TRANSITIONS:**

- Create inter/multidisciplinary teams in hospitals and in the community to assist with care transitioning and coordination of services including social and psychological supports and community re-integration.

## **KNOWLEDGE AND AWARENESS OF NEUROLOGICAL CONDITIONS:**

- Educate primary health and community-based providers about NC-specific conditions using newer technologies and informational CDs and DVDs.
- Provide education and support materials to all service providers, emergency room clinicians, family physicians and caregivers.
- Teach the theoretical basis and best practice for self-management to providers and others who support Persons with NCs.

## **INTERSECTORAL COLLABORATION:**

- Create 'coordinator/navigator role' to facilitate communication and link to services.
- Create opportunities for specialists to consult with one another.

# PERSON-CENTERED HEALTH SYSTEM

## **ACCEPTANCE AND OPENNESS TO NEUROLOGICAL CONDITIONS:**

- Promote a paradigm/culture shift to view the whole person as opposed to the condition as they age and change our understanding of success in relation to their NC across their lifespan

## **SUPPORTED TRANSITIONS:**

- Create day programs and extend educational opportunities for young adults with NCs

## **CAREGIVER SUPPORT:**

- Streamline and reduce paperwork for Persons with NCs and caregivers when applying for government tax credits

## **INTERSECTORAL COLLABORATION:**

- Create shared assessments across multiple ministries to improve linkages and cooperation
- Improve access to electronic medical records across sites

# PERSON-CENTERED HEALTH SYSTEM (cont'd)

## **KNOWLEDGE AND AWARENESS OF NEUROLOGICAL CONDITIONS:**

- Need government and community based organizations to increase efforts to make their websites accessible, credible and easy to navigate in both English and French
- Provide trusted 'one-stop shop' online platforms and databases (e.g. for signs and symptoms, things you need to do now, best practices, resources and services) for Persons with NCs, families, caregivers and health care professionals
- Develop and implement practice guidelines and tools e.g. for rare conditions

## **AVAILABILITY and ACCESS to SERVICES:**

- Expand Telehealth infrastructure to accommodate greater use for care and training, linking with diagnostic images and use in homes of Persons with NCs
- Create a toll-free help line for Persons with NCs and caregivers
- Improve access to specialists and care teams with expertise to provide accurate diagnosis

# HEALTHY PUBLIC POLICY

## **ACCEPTANCE AND OPENNESS TO NEUROLOGICAL CONDITIONS:**

- Increase public awareness and acceptance of NCs to reduce stigma and promote social inclusion among the general public (e.g. in schools, among service providers and employers)

## **EVIDENCE-INFORMED POLICY:**

- Change policy mindset from restrictive and short termed focus to investing in the long term
- Need national implementation of practice guidelines

## **INVESTMENTS and FUNDING:**

- Introduce non-categorical needs-based funding programs and move away from the bio-medical focus
  - Need uniformity of drug policies across provinces
  - Increase consistency in funding across ministries for children and adults with NCs
- [...]

# HEALTHY PUBLIC POLICY (cont'd)

## INVESTMENTS and FUNDING (cont'd):

- Create more flexible policies for Persons with NCs and caregivers (e.g. Employment benefits, CPP, medication, disability tax credits, sick/compassionate care, equipment programs, and assistive devices program).
- Extend length of time available for receiving benefits
- Create an income support plan specifically for Persons with NCs that lessen restrictions around earnings while receiving government assistance to promote employment
- Eliminate criteria tying employment to receiving caregiver benefits
- Enable Persons with NCs to secure personal insurance

[...]



# HEALTHY PUBLIC POLICY (cont'd)

## LIFE ENHANCING RESOURCES:

### ➤ *Employment*

- Increase workplace policies and create incentive programs that encourage employers to hire and accommodate Persons with NCs
- Increase opportunities for Persons with NCs to participate in post-secondary education, training and employment

### ➤ *Housing*

- Create affordable and accessible housing that is age specific and appropriate for Persons with NCs
- Enforce accessibility requirements (e.g. building codes)

### ➤ *Transportation*

- Provide affordable and accessible transportation in both urban and rural areas for Persons with NCs and caregivers to get to their medical appointments/programs

## AVAILABILITY and ACCESS to SERVICES:

- Change HHR policies to increase specialists with expertise in NCs



**Dr. Susan Jaglal**

Toronto Rehabilitation Institute-UHN  
Chair at the University of Toronto  
Department of Physical Therapy  
160 - 500 University Avenue  
Toronto, ON M5G 1V7

**Telephone:** 416-978-0315

**Email:** [susan.jaglal@utoronto.ca](mailto:susan.jaglal@utoronto.ca)