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# A Focus of Health Care Reform: managing physical disabilities/complex patients in primary care

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# Faculty/Presenter Disclosure

- Faculty: Dr. James Milligan
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# Disclosure of Commercial Support

**This program has received financial support from Ontario Neurotrauma Foundation in the form of a development grant.**

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James Milligan has received funding from the Ontario Neurotrauma Foundation.

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# Mitigating Potential Bias

- Funding has been provided for development and improvement in healthcare services and not for proprietary gain.

# Objectives

- Disability and Healthcare
  - provider perspective
  - patient perspective
- a model for change
- roles of team members
- outcomes
- challenges/successes
- future plans

# Disability & Healthcare: a global issue

- Across the world, more often than their non-disabled peers, people with disabilities do not receive the health care they need and have poorer health (WHO World Report on Disability, 2011)
- "As a society, we are judged on how we treat our disempowered populations...unfortunately it is the most marginalised in our community who suffer the most from the failings of the current health system." (A Healthier Future for All Australians, 2009)

- Health care system failures are most poignant with complex-needs patients. Due to severe or multiple health conditions and functional limitations, are more likely to go to hospitals, emergency rooms, and long-term care facilities, and to need more supportive services to help with activities of daily living . They are more vulnerable to fragmented care and “falling through the cracks.”(Agency for Health Research and Quality (AHRQ), 2012)
- “its like a pick-up soccer game in which the participants were playing together for the first time, didn’t know each other’s names, and wore earmuffs so they couldn’t hear one another.” (Lawrence, 2003)

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# Disability & Healthcare: closer to home

"Ontario is improving care for seniors and others with complex conditions...brings together health care providers...to better and more quickly coordinated care for high-needs patients" (MOHLTC, 2012)

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# Disability

- an umbrella term for impairments, activity limitations and participation restrictions…the interaction between individuals with a health condition (cerebral palsy, depression) and personal and environmental factors (negative attitudes, inaccessibility, limited social supports).
- complex interaction between a person's body and features of society, overcoming the obstacles requires interventions to remove environmental and social barriers (WHO, 2011)

“disability” means,

(a) any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness and, without limiting the generality of the foregoing, includes diabetes mellitus, epilepsy, a brain injury, any degree of paralysis, amputation, lack of physical co-ordination, blindness or visual impediment, deafness or hearing impediment, muteness or speech impediment, or physical reliance on a guide dog or other animal or on a wheelchair or other remedial appliance or device,

(b) a condition of mental impairment or a developmental disability,

(c) a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or spoken language,

(d) a mental disorder, or

(e) an injury or disability for which benefits were claimed or received under the insurance plan established under the Workplace Safety and Insurance Act, 1997; (“handicap”) (Accessibility for Ontarians with Disabilities Act AODA 2005)

# We've come a long way...

## Using words

| Don't say | Say |
|---|---|
| the cripple | a person with a disability |
| crippled | a person with a physical disability |
| lame | a person who uses a wheelchair |
| physically challenged | a person with arthritis |
| confined to a wheelchair | |
| wheelchair bound | |


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# The Magnitude

- 1 in 7 Ontarians has a disability... 1 in 5 by 2036
- Accessibility for Ontarians with Disabilities Act 2005- make Ontario accessible by 2025

Ontario Ministry of Economic Development, Trade and Employment

# Why Accessibility is good for Ontario

**ac'ces'si'bil'i'ty** [ak-ses-uh-bihleetee] noun
Accessibility simply means giving people of all abilities opportunities to participate fully in everyday life.

## now

**1 in 7** people in Ontario have a disability, that's **1.85 million Ontarians.**


## soon

By 2036, that number will rise to **1 in 5** as the population ages.


**Customers with disabilities are a growing market no business can afford to overlook.**


In the next 20 years, an aging population and people with disabilities will represent **40% of total income in Ontario** — that's **$536 Billion.**

**360,000**
Ontario businesses and organizations affected by Ontario's accessibility law. It helps them meet the needs of people with disabilities and **attract their growing spending power.**


**A more accessible Ontario is good for our economy and our communities.**

**Improved accessibility in Ontario can help generate up to:**

**$9.6 Billion** in new retail spending **&** **$1.6 Billion** in new tourism spending

**To learn more about how we are making Ontario more accessible, visit: ontario.ca/AccessON**

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Data credits:
- Ontario Ministry of Community and Social Services
- Ontario Population Projections 2008-2036, Fall 2009 Ministry of Finance Report
- Participation and Activity Limitation Survey 2006, Statistics Canada
- Martin Prosperity Institute, Releasing Constraints: Projecting the Economic Impacts of Improved Accessibility in Ontario, June 2010

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# Disability & Healthcare: the realities

- People with disabilities utilize health care more but greater unmet needs (utilize ER, hospitals)(part of the 5% that utilize 2/3 of healthcare resources)(Young et al, 2005;ICES 2008)
- Secondary conditions- predictable and preventable (pressure ulcers, UTIs, osteoporosis)
- Co-morbid conditions- increased diabetes, cardiovascular disease (Sharts-Hopko et al, 2003)
- Premature Ageing- begins earlier (Dejong, 2003)
- High health risk behaviours- smoking, drugs, inactivity
- Social issues- decreased supports, high unemployment, affordable housing, transportation

# Disability & Healthcare: the realities

- Difficulty finding a primary care provider (Young et al, 2005; McColl et al,2008)
- More and different health care providers (AHRQ, 2012), complex navigations (Donnelly, 2007)
- Thinner margin of health (Canadian Disability Policy Alliance, 2012)
- Health promotion and prevention seldom targets those with disabilities (screening, education, even weight check)(WHO, 2011; McColl et al, 2008)

# Disability & Healthcare: patient perspective

- Barriers- physical access and transportation, funding, provider attitudes, communication gaps, and health systems failures.
- Gap in knowledge- primary care providers and other health professionals need more education about disability needs
- Attitudes- cultural sensitivity & disability awareness

Morrison et al, 2008

# Disability & Healthcare: provider perspective

- Accessibility
  - many physicians feel office is accessible (Shankardass et al, 2003)
  - patient who need assistance or need their own attendant; don't have specialized equipment; less likely to examine patient if impediments such as dressing/undressing, communication
  - small proportion of patients in any given practice that require specialized equipment does not justify equipment expenditures (Lee et al, 2011)

# Disability & Healthcare: provider perspective



- Gaps in knowledge
  - how to:
    - access disability resources, coordinate care and adapt health maintenance visits, address sexuality/contraception, order durable medical equipment, complete forms for disability status and home care, and plan for hospital discharge (Morrison et al, 2008)
    - never received training or little of it in medical school/residency (Lee at al, 2011)
    - low prevalence of disabled patients, physicians are challenged to remain updated on best practices with minimal exposure to health issues associated with severe mobility impairments (McColl et al, 2013).
    - often miss preventative health as doing episodic care (McColl et al, 2008; Lee et al, 2011)

# Disability & Healthcare: provider perspective

- Attitude
  - physicians noted that they interacted differently with disabled and non-disabled patients. (McColl et al, 2008)
  - patient can take the role of teacher (Lee et al, 2011; McColl, 2008)
    - disabled patients are notably different from non-disabled – take longer, more complex, more coordination. (McColl et al, 2008)
- Systemic
  - lack of specialist support or lengthy waiting lists
  - lack of financial incentive (Lawther et al, 2003)

# Recommendations

Education:

- professionals and trainees about disabilities and resources, enhancing physical access (eg, high-low examination tables, wide automatic doors, high-contrast signs and lighting, wheelchair scales), and increasing appointment times. (Morrison et al, 2008)
- Family medicine educators can begin by teaching learners how to coordinate care, access resources, and communicate about disability issues. (Morrison et al, 2008)

# Recommendations

Communication:

•“cross-training” for all health professionals, from front office staff to clinicians (Morrison et al, 2008)

Coordination:

•the ‘lubricant’ that facilitates links for all areas of quality for a person with disability, presents the most significant opportunity for improvement, because multiple medical and social providers are typically involved in the care of individuals with disabling conditions (Lawther et al, 2003)

# Recommendations

Team:

- Health care providers need to embrace a multi-disciplinary approach to meet the needs of persons with disabilities (McColl et al, 2006)
- "There are 2 models of primary care delivery in Ontario that appear best suited to delivering integrated primary care to people with disabilities and chronic diseases - the Community Health Centre model and the Family Health Team model"

# Recommendations

- McColl (2006) found a shared care model was attractive to physicians, who valued the learning opportunity and the specialist perspective but still maintaining involvement with their patient
- In the survey by Lee et al, 2011 physicians perceived themselves as ill-prepared to meet the care needs of these patients; given that all of the physicians were from family health teams, it might have been predicted that they would have perceived themselves to have a greater degree of supports (allied health professionals) available to manage these patients.

# Recommendations

- Lee et al, 2011 heard from physicians that it may be better to have centralized locations within the region that were fully accessible with specialized equipment rather than outfitting all offices.
- Access to specialized mobility clinics within primary care settings perceived advantages:
  - Timely access (avoid hospital)
  - Comprehensive assessment, care planning
  - Care coordination
  - Could leverage specialist support

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# Mobility Clinic

Goals:

•improve access to quality interprofessional healthcare (“level the playing field”)

•support patient, family, caregiver and primary care provider

•help to coordinate services

•to promote awareness of mobility related issues

•to develop further clinical, education, research projects involving individuals with mobility issues

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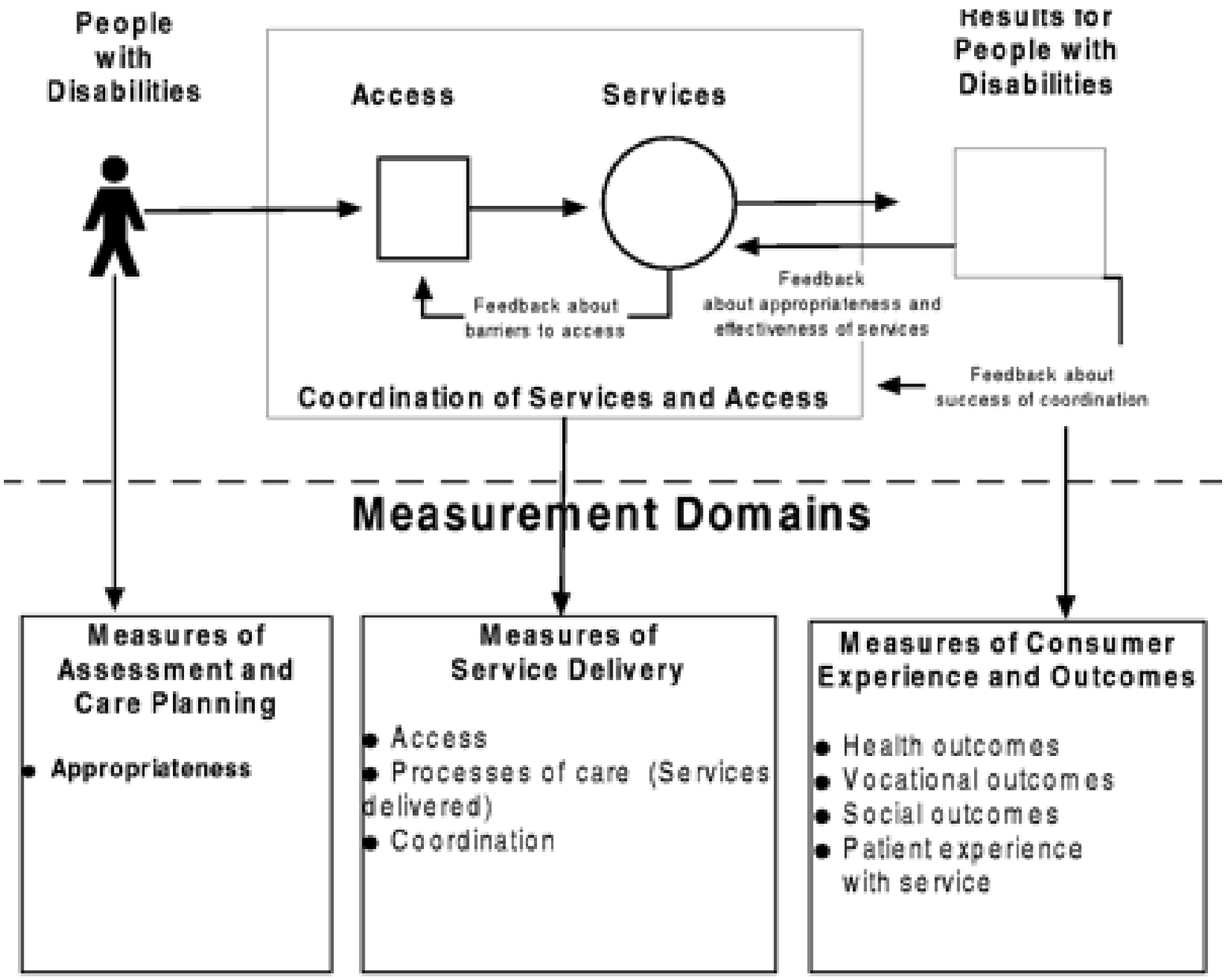
**Mobility Clinic program logic model**

| Program Activities | Provision of a fully accessible Mobility Clinic | Provision of Primary Care for Adults with Mobility Impairments | Capacity Building (Healthcare Professionals) |
|---|---|---|---|
| **Outputs** | Fully accessible medical building, office and examination room<br>No. and type of accessibility features/equipment<br>No. and type of disciplines | No. of referrals<br>No. of patients seen<br>No. assessments conducted<br>No. of follow-up visits<br>No. of visits (total)<br>No. of providers accessed | No. of education sessions delivered (clinic rotations, presentations, workshops)<br>No. of participants<br>No. of resources/materials developed |
| **Short-term outcomes (1–3 years)** | Implementation of an accessible primary care clinic<br>Patient satisfaction with physical space (accessibility, appropriate equipment)<br>Patient satisfaction with access to clinic<br>Patient satisfaction with access to inter-professional care | **Patient-related impacts:**<br>• Improved access to comprehensive assessment and care<br>• Improved access to accessible care and specialized equipment<br>• Increased access to primary care<br>• Increased access to inter-professional care<br>• Improved quality of care<br>• Improved health outcomes<br>**Health-system related impacts:**<br>• Reduced burden of care for healthcare providers<br>• Reduced barriers to care<br>• Timely access to care that is local<br>• Reduced hospitalization and institutionalization due to fewer falls and access to quality care that supports patients to live at home longer | Increased access to education/ training regarding mobility impairments<br>Increased awareness of issues associated with mobility impairment<br>Increased capacity for managing patients with mobility issues<br>Perceptions of improved management of adults with mobility impairments<br>Achievement of specific performance objectives associated with education initiatives<br>Enhanced awareness of available community supports and resources<br>Improved (changed) attitudes toward caring for those with mobility impairments |
| **Long-term outcomes (>3 years)** | Reduced hospitalization and institutionalization due to fewer falls and access to quality care that supports patients to live at home longer<br>Reduced inappropriate/unnecessary visits to the emergency department<br>Improved early detection and intervention of health issues | | |
| **Impact** | Improved health system capacity to provide care to adults with mobility impairment<br>Enhanced quality of healthcare to adults with mobility impairments<br>Improved health outcomes of adults with mobility impairments | | |

Lee et al, 2013


People with Disabilities
Access
Services
Results for People with Disabilities
Feedback about barriers to access
Feedback about appropriateness and effectiveness of services
Feedback about success of coordination
Coordination of Services and Access
Measurement Domains
Measures of Assessment and Care Planning
Appropriateness
Measures of Service Delivery
Access
Processes of care (Services delivered)
Coordination
Measures of Consumer Experience and Outcomes
Health outcomes
Vocational outcomes
Social outcomes
Patient experience with service

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# Mobility Clinic

Access:

- physically accessible
- address preventative care
- flexibility of appointments
- longer appointments
- in home visits
- transportation (Mobility Plus)
- services (CCAC, independent living)

Attitudes:

- sensitivity training
- accommodation to specific needs

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# Mobility Clinic

Knowledge/Competence:

- interprofessional approach to maximize expertise
- managing complex patients helps ease demand to individual family physician
- team members act as resource to PCP
- develop resources for point of care use
- link to specialist care

Systemic:

- facilitate coordination- point of contact, follow-up longer appointments

# Team

Family physician

Chiropractor

Occupational Therapist

Social worker

Nurse

Pharmacist

Physiotherapist

Community supports

# Mobility Conditions

- neurological- spinal cord injury, multiple sclerosis, cerebral palsy, CVA, brain injury, Parkinson's
- musculoskeletal- myotonic dystrophy, muscular dystrophy, rheumatoid and osteo arthritis

# Description

- 1/2 day per week with support 5 days per week
- number of patients seen (2012)- 146
- new patients- 98
- total visits- 211
- follow-up visits- 113
- average wait to assessment- 6.7 weeks
- length of assessment- 2 hours (new patient)

# Team Roles

**Nursing:**

- gather patient goals
- collect current and past medical history
- record medications
- vitals: BP, HR, RR, orthostatic, visual acuity, weight (wheelchair scale), height
- help transfer (overhead lift)

# Team Roles

**Occupational Therapist:**

- review of function- ADL, IADL
- home coping assessment (consideration of home assessment)
- cognitive assessment
- help transfer
- assessment gait aids/wheelchair
- perform gait/balance assessment (TUG; Tinetti)

# Team Roles

## Chiropractor/Physiotherapist:

- musculoskeletal/neurological examination
- help transfer
- gait/balance assessment (TUG; Tinetti)
- prescription of exercise

# Team Roles

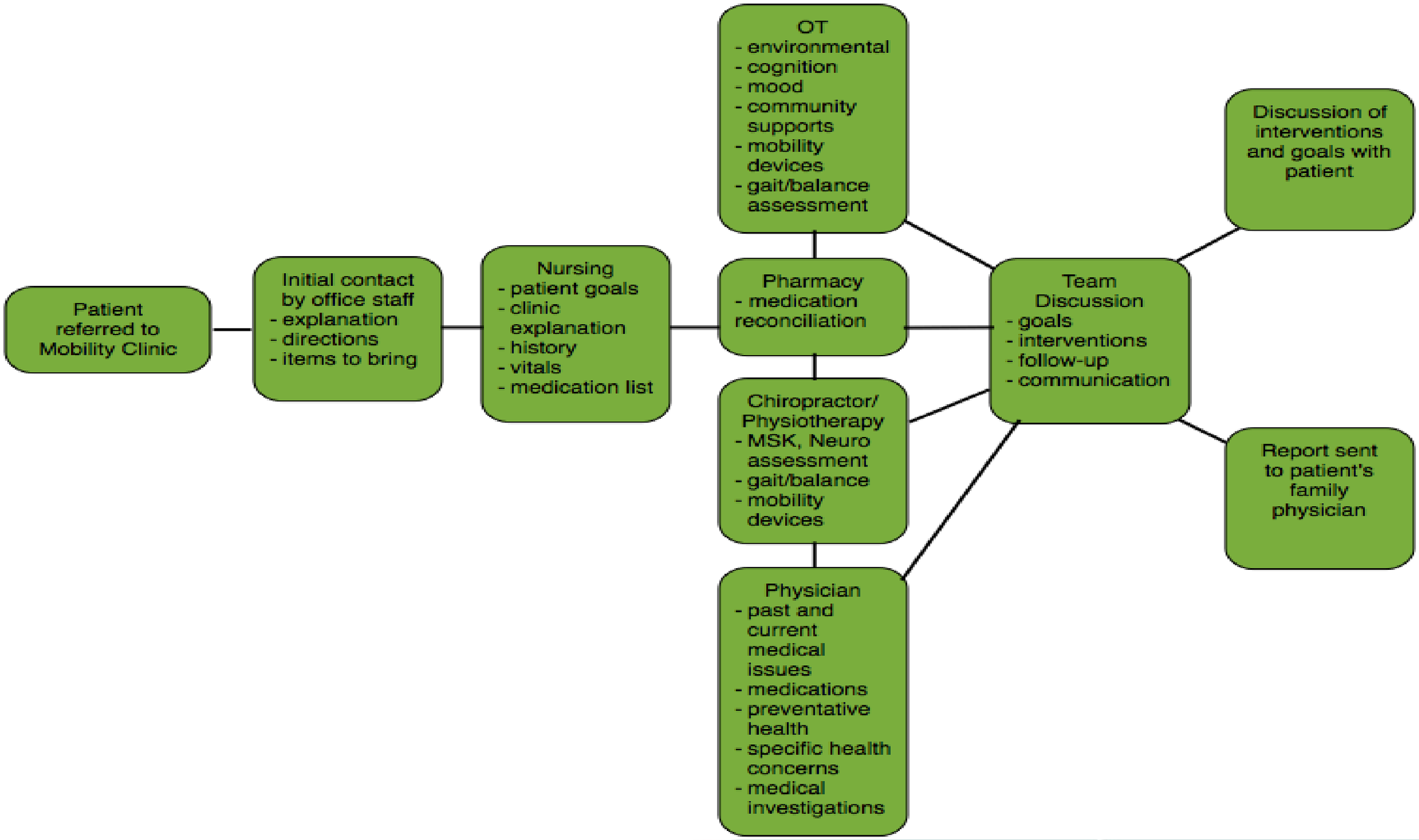
**Pharmacist:**

- adherence to medications
- safety (blister pack)
- interactions
- identify unnecessary medications

# Team Roles

**Physician:**

- review medical history
- review investigations (imaging, bloodwork)
- preventative health


Patient referred to Mobility Clinic
Initial contact by office staff
- explanation
- directions
- items to bring
Nursing
- patient goals
- clinic explanation
- history
- vitals
- medication list
OT
- environmental
- cognition
- mood
- community supports
- mobility devices
- gait/balance assessment
Pharmacy
- medication reconciliation
Chiropractor/ Physiotherapy
- MSK, Neuro assessment
- gait/balance
- mobility devices
Physician
- past and current medical issues
- medications
- preventative health
- specific health concerns
- medical investigations
Team Discussion
- goals
- interventions
- follow-up
- communication
Discussion of interventions and goals with patient
Report sent to patient's family physician

# Description

Interventions:

- Preventative care- pap, BMD,
- Medication adjustment- discontinue or adjust ; vitamin D; calcium
- Exercise prescription
- Home visit
- Coordination of services- CCAC, wound care
- Referral to specialist- physiatry, neurology
- Investigations- EMG, MRI, bloodwork

**Summary of the factors facilitating and challenging the development and implementation of the Mobility Clinic**

| Facilitating Factors | Challenges |
|---|---|
| Physical accessibility and specialized equipment<br>Promotion (marketing) of the clinic<br>Partnership with the Canadian Paraplegic Association<br>FHT leadership support<br>Learnings and support from the CFFM Memory Clinic<br>Flexibility to meet needs of patients | Increased demand for service<br>Broad range of mobility issues poses a challenge to the overall vision and focus of the clinic<br>Clinic accepts only patients rostered with the CFFM FHT<br>System issues, which threaten the effectiveness of the clinic:<br>• CCAC unable to accommodate or modify service recommendations<br>• Cost of private services precludes its use by some patients<br>• Inaccessible laboratories and specialist offices |

CCAC = community care access centre; CFFM = Centre for Family Medicine; FHT = family health team.

Lee et al, 2013

# Successes

Access

- established a functional space within a typical family practice with minimal cost
- more comprehensive assessment allowed due to adequate time
- improved support to patient and PCP (burden off PCP, resource outside of regular clinic hours ie. message question regarding patient care)
- initial engagement of physicians outside of FHT

Attitudinal

- transformation in the approach to those with physical disabilities and their specific/unique needs

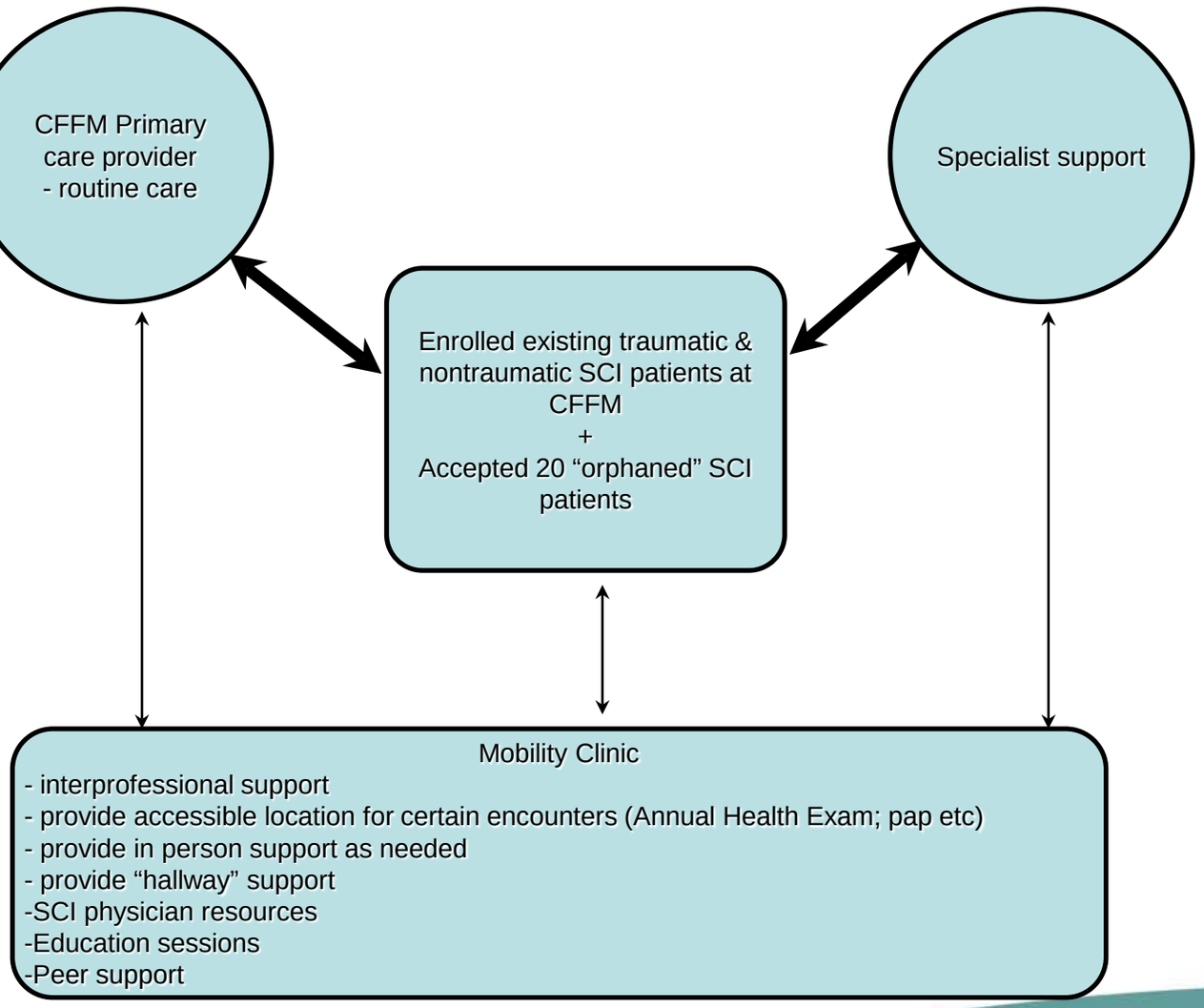
Knowledge

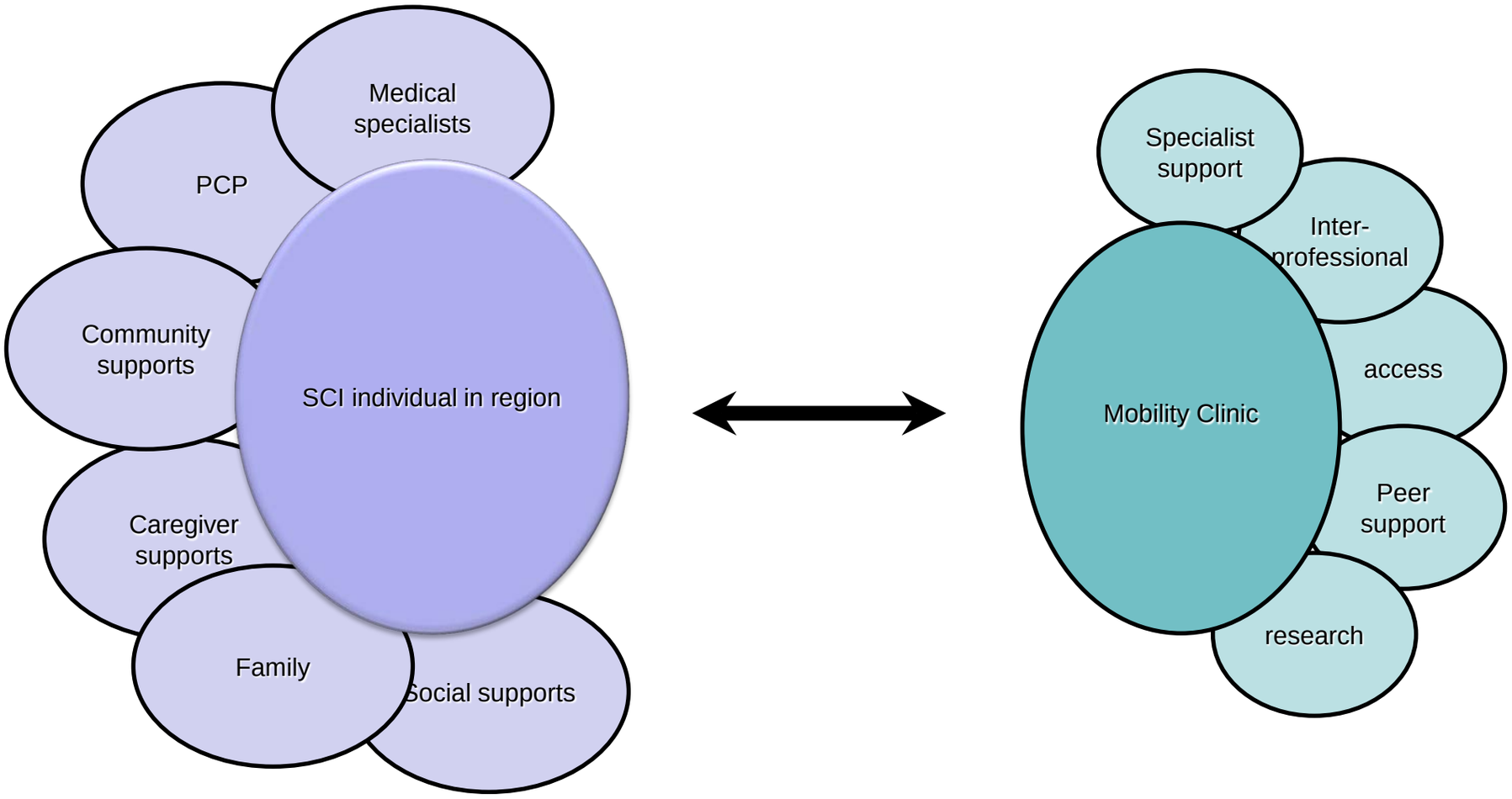
- interprofessional team members bring expertise, translate knowledge to others, have expanded each scope of practice and broken down barriers within own professions
- team members gained valuable skills that are transferable across many different sub groups in this population
- regular PCP and medical learners have benefited from knowledge translation
- collaboration with researchers

Systemic

- coordinated care
- linking specialist care in unique ways

# Translating the model: spinal cord injury in primary care




Medical specialists
PCP
Community supports
SCI individual in region
Caregiver supports
Family
Social supports
Specialist support
Inter-professional
access
Mobility Clinic
Peer support
research

Identification of key healthcare priorities:

- preventative care
- PCP knowledge to SCI issues
- access to specialist care
- integration/coordination of care
- identification of best practices (bladder, bowel)
- peer support group
- broader translation to all physically disabled

Initiatives:

- Annual physical examination- regular preventative care and specific SCI care
- Support to PCP for SCI related enquiries
- SCI Physician Template
- SCI Consumer Self-Management Toolkit
- SCI Physician Resources
- Identifiers in patient chart for key health related concerns
- Coordinating care with specialists
- Electronic consultation with physiatry
- Collaboration with research in SCI
- Establishment of exercise programs for those with neurological conditions at YMCA

# Essentials

- Champions
- Flexibility
- Supportive Team
- Identification of target population

# Future

In line with health care priorities

- Health Links
- Leverage the common issues in disability
- Coordination and integration- reduce the fragmentation
- Global collaboration
- Evaluate, refine and disseminate model

# Summary

Although people with disabilities represent a heterogeneous group, with much variation in environmental circumstances and needs, some quality of care issues are universal:

- Access- physical access barriers still exits but also other important access issues include access to assistive technology, access to medications, transportation, timely or time of appointment.
- Attitudes- society, providers, staff
- Quality- inadequate preventive care, under-recognition or under-treatment of co-morbid conditions, and barriers to effective provider–client communication.

  Barriers may be addressed at the provider level:

  structured approach to care management

  use of preventive care flow sheets, or provider and consumer reminders

- System/Coordination of Services-

  providers must work within a delivery system that both allows adequate time for client visits and increases the availability of mid-level practitioners who can fill in the information and communication gaps.

  Funders of care need to re-think payment strategies so that case management, care coordination and time with the client are reimbursed.

(Lawther et al, 2003)(McColl)

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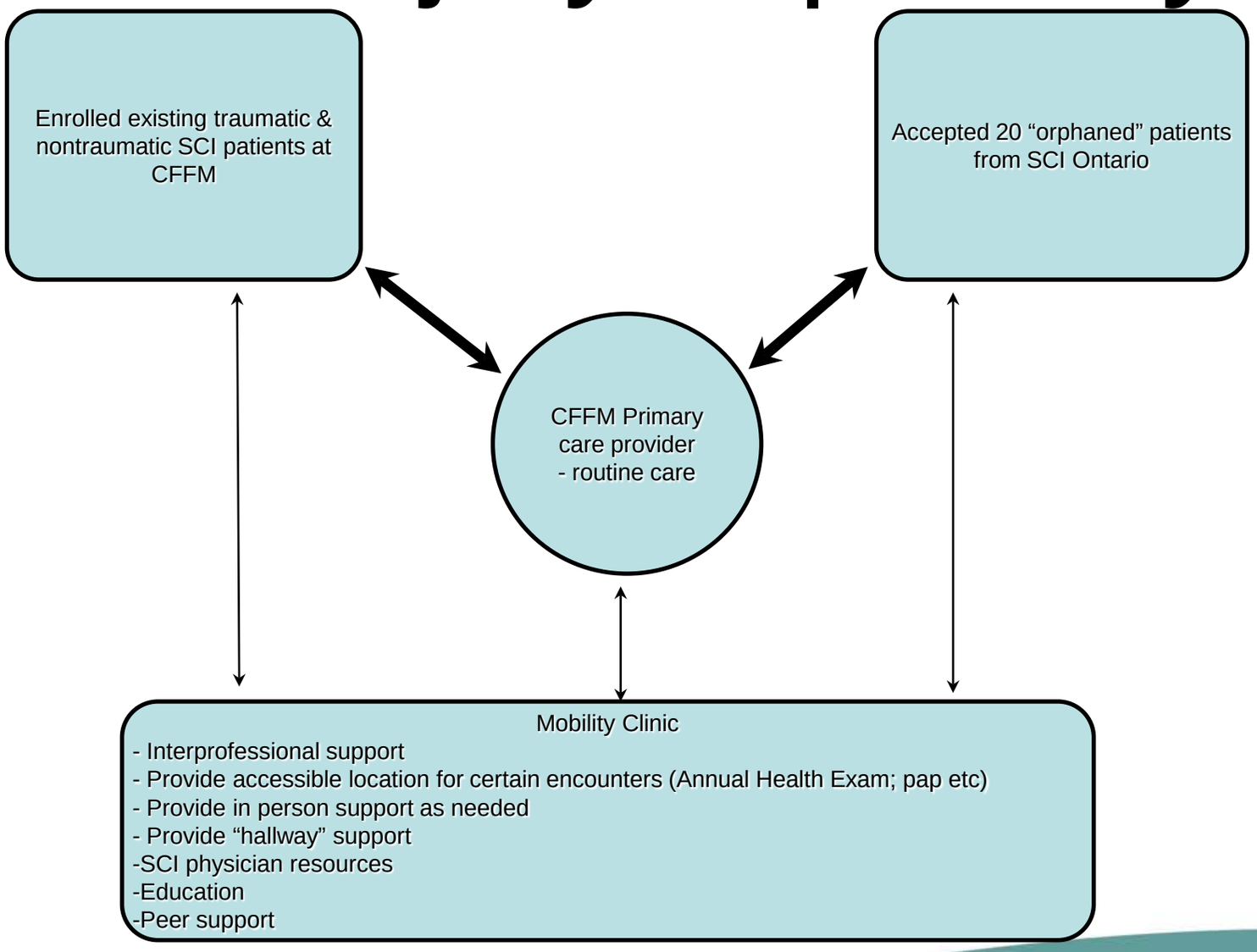
•Rethinking the design of service delivery for persons with disability leads to a system that integrates and coordinates medical, social and vocational services. The system should focus on issues of access, processes of care, coordination, and client outcomes. (Lawther et al, 2003)

# Translating the model: spinal cord injury in primary care



- We propose a model of quality that is based on high quality medical, social, and vocational services (appropriate, effective, safe, and timely care), and also acknowledges the importance of a first-rate experience with care (communication, respect for preferences), excellent access to care (physical, financial, cultural, geographical), and superior coordination of care. Application of the model requires the integration of traditional medical services, with services provided by agencies that address vital social needs such as housing, medical supply, transportation, and vocational and educational services. These non-medical services make a substantial contribution to a person reaching their full potential in terms of personal, vocational, and societal fulfillment.

- A patient-centered medical home provides team-based care that is integrated and coordinated by primary care physicians (PCPs) for all patients in a practice. (Yee et al, 2012) PCMH- “the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community” (AHRQ, 2012).
- While similar to a patient-centered medical home, high-intensity primary care programs differ in that they focus only on the sickest, highest-cost patients in a given group, providing them with additional care coordination, management and health education far beyond what is offered in traditional primary care practices.
- Early assessments indicate high-intensity primary care programs, sometimes called ambulatory intensive care units, or AICUs,2 appear to be effective in the small number of settings where they have been tested to date.
- (Yee et al, 2012)