Institute of Health Policy, Management & Evaluation
UNIVERSITY OF TORONTO

Toward A Person-Centred Continuum of Places for Care Over the Longer Term

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IHPME

www.ihpme.utoronto.ca

A Brief Word About the Presenter

- Professor Emeritus: Health Policy
  - Dalla Lana School of Public Health, University of Toronto
- Knowledge Creation: Balance of Care Research Group
  - Costs & outcomes of community-based care for high needs persons & caregivers (older persons, persons with disabilities, children with complex medical needs)
  - “On-the-ground” studies in 12 of 14 health regions in Ontario including North Shores Tribal Council (Mamaweswen)
- Knowledge Mobilization: Canadian Research Network for Care in the Community
  - England, Mexico, China, Netherlands, Middle East, South Korea, Japan
- Board Member & Volunteer
  - Ontario Community Support Association, Anne Johnston Health Station, Bellwoods Centres for Community Living, Carefirst Seniors

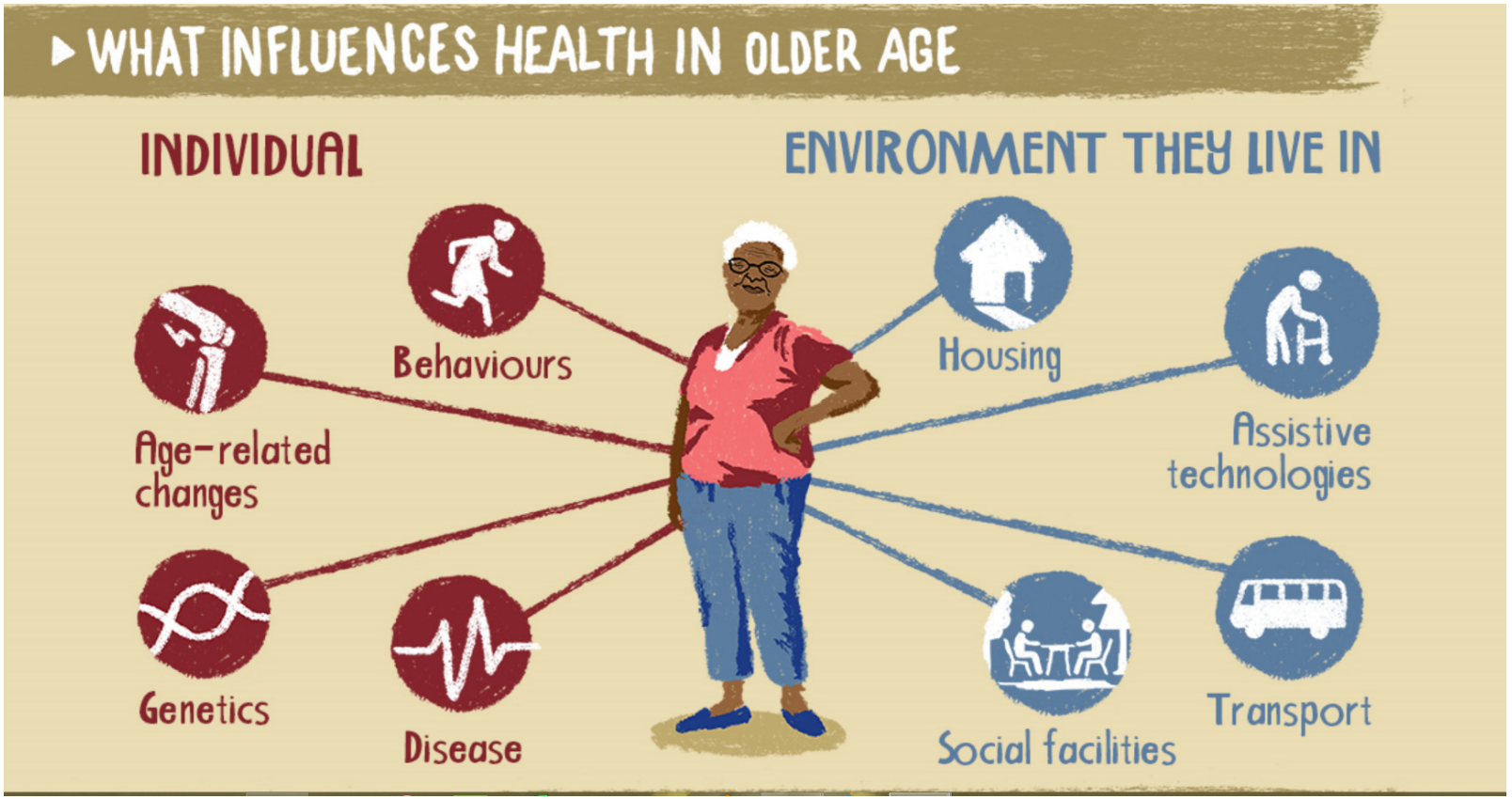
Part 1: Where We Are Now

Five Key Challenges

Challenge 1:
Still Focused on Health Care, Not Health

- In Canada, preoccupied with *health care services*
  - Universal access to medically necessary hospital and doctor care
  - Often provider-centred
  - Accountability for services
- World Health Organization focused on *health*
  - What it takes to maintain wellbeing, functional status and quality of life of individuals and communities
  - Always person-centred
  - Accountability for care

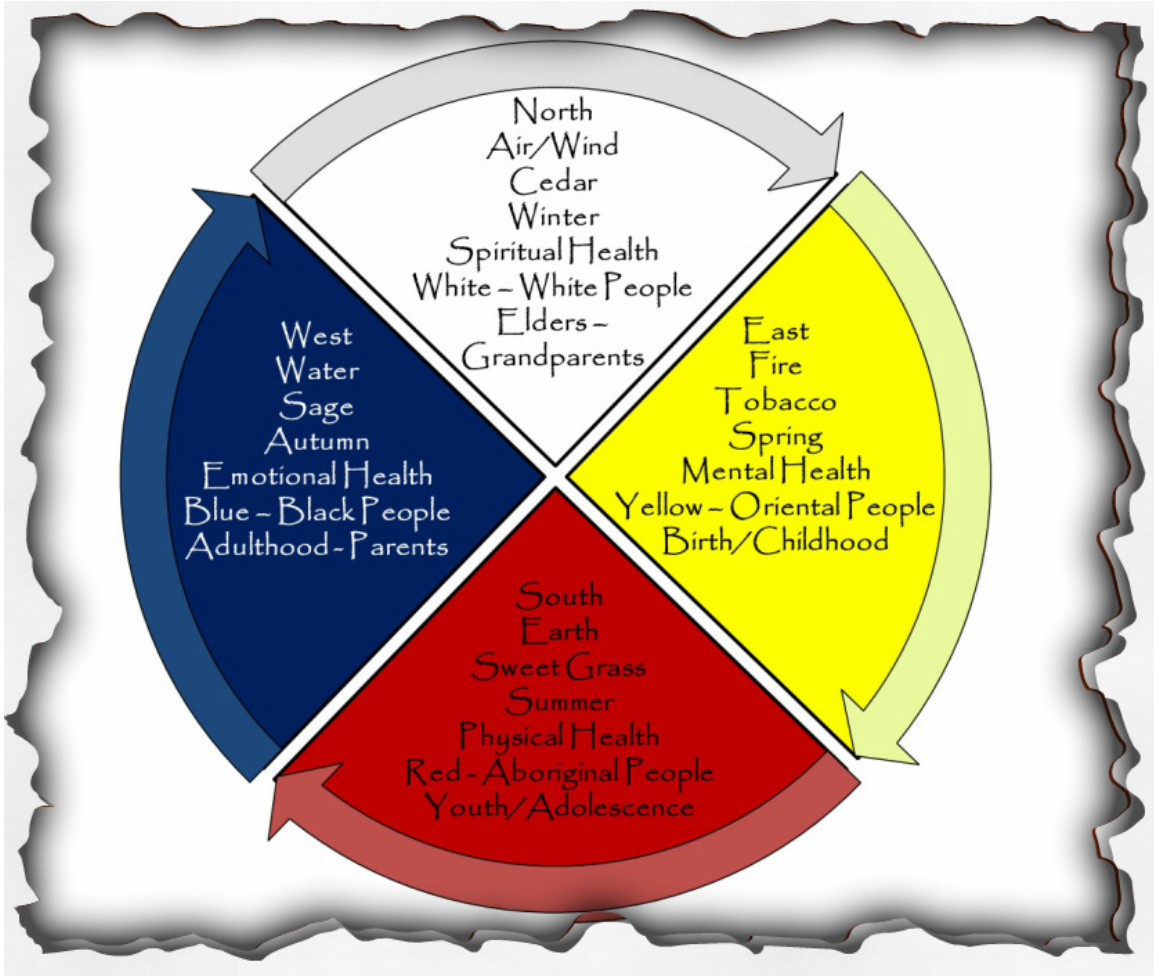
Health and Wellbeing of Older Persons:
Health Care Only One Factor



Source: World Health Organization. Healthy Aging. 2015. http://www.who.int/ageing/events/world-report-2015-launch/healthy-ageing-infographic.jpg?ua=1

The Medicine Wheel:

Spiritual, Emotional, Mental & Physical Health



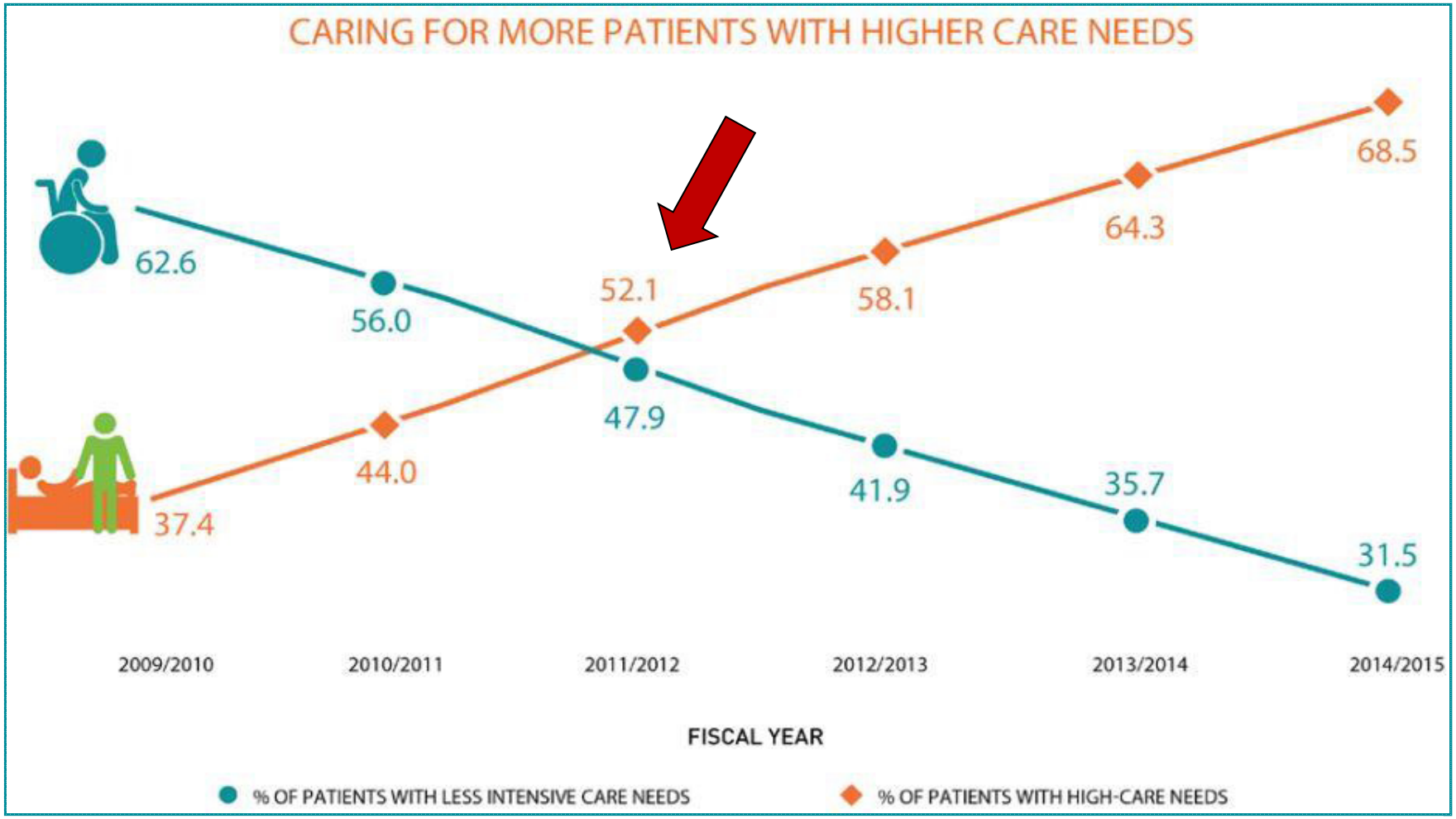
Source: http://ojibweresources.weebly.com/medicine-wheel.html

Challenge 2:
Still Focused on Beds, Not Places

- Most older Canadians want to stay in their own homes and communities
  - As independently as possible for as long as possible close to family and social networks
  - Home, assisted living, supported housing, day programs
  - Culturally competent care
- Yet, political debate often focused on beds
  - In Ontario, declining access to “before-the-fact” home and community care

Home Care Conundrum:

Decline of "Before-the-Fact" Care in Ontario



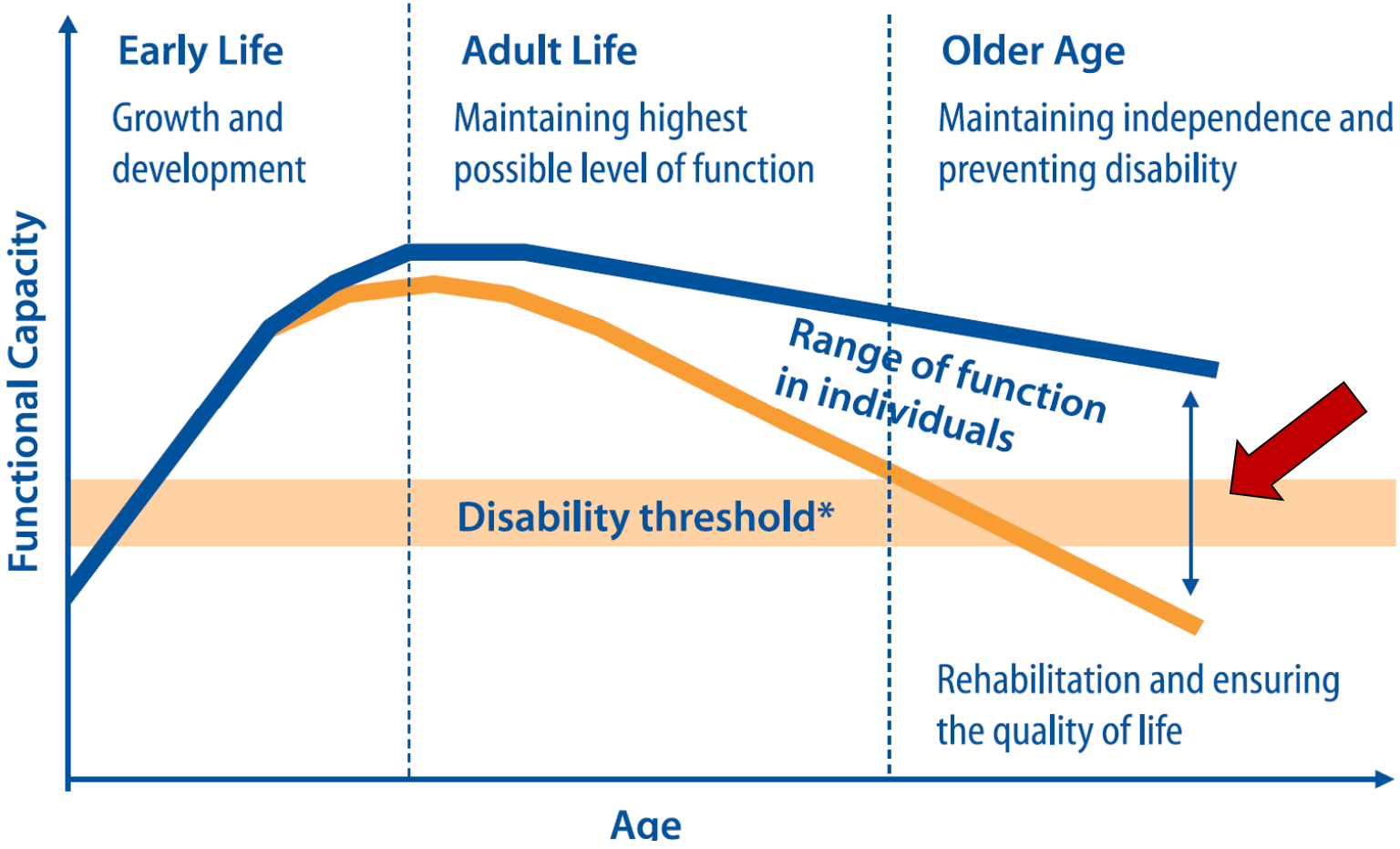
Source: Ontario Association Of Community Care Access Centres, 2016

Beds by Default: A Downward Spiral

- Lacking community-based care, too many older persons end up in hospitals with few discharge options (also adding to ER waits and "ALC")
- Because hospitals not designed to meet "restorative, supportive and rehabilitation needs," extended hospitalization increases the likelihood of "default" to residential LTC

Challenge 3:

Older Canadians Healthier, With More Gains Possible



Source: WHO. Active Aging. http://apps.who.int/iris/bitstream/10665/67215/1/WHO_NMH_NPH_02.8.pdf

Not All Good News: Many Older Canadians Still Face Everyday Challenges To Wellbeing

General Health and Well-being

Self-reported health is an important indicator of overall health and well-being, and can help predict disease and death.

74% of Toronto seniors rated their general health as good, very good or excellent in 2013/14

- **26%** said their health is fair or poor
- Less favourable than the rest of Ontario[9]

81% of high income seniors rated their health as good, very good or excellent vs. **66%** in the lowest income group.[9]

Disability

39% of seniors had some type of physical or mental disability in 2012[15]

27% needed help with one or more daily tasks in 2013/14, including preparing meals, doing housework, personal care, going to appointments, running errands and paying bills[9]

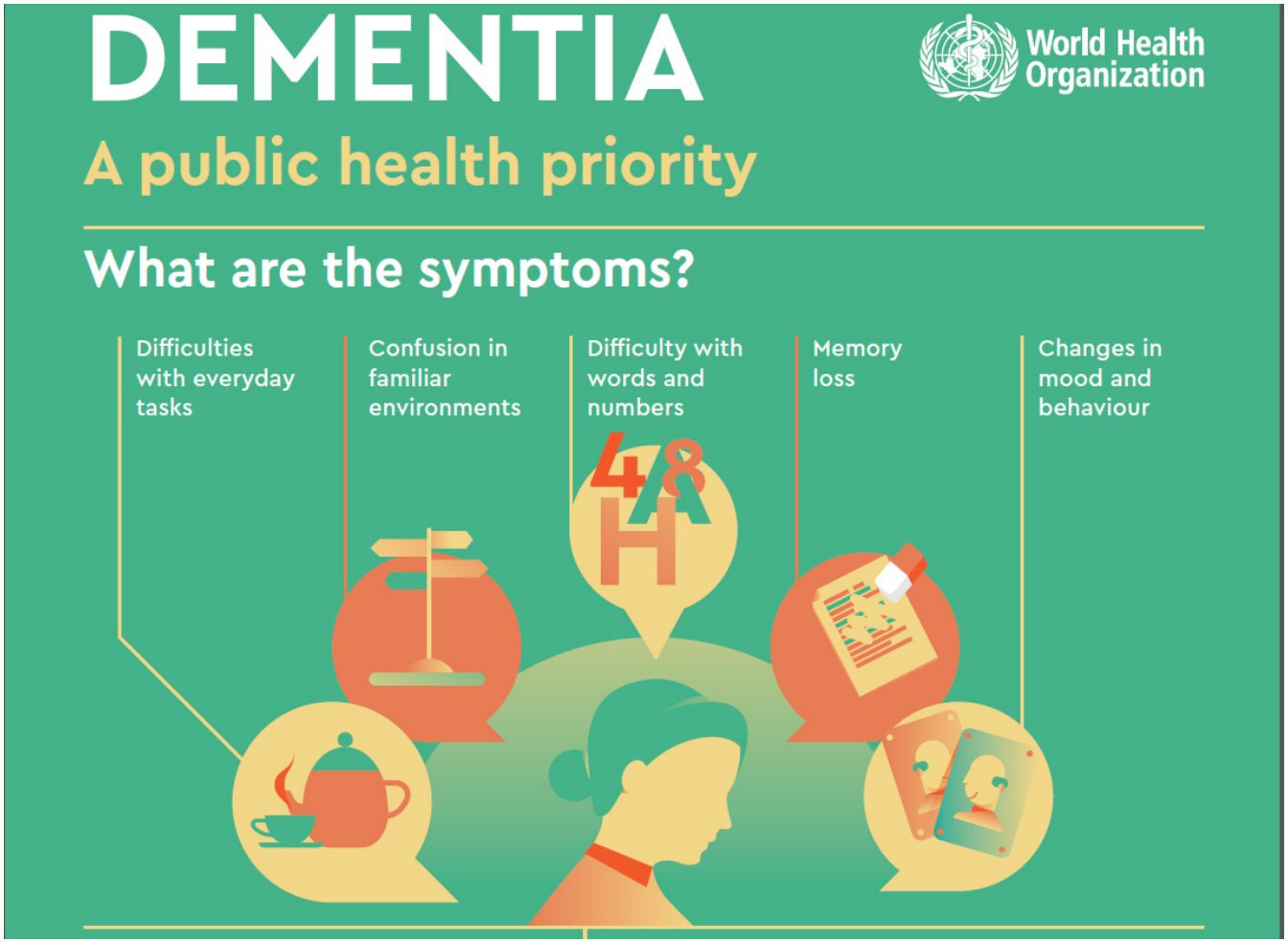
Mobility

80% could walk without difficulty in 2013/14

20% had difficulties with mobility, including having trouble walking, needing equipment to walk, needing a wheelchair and needing help from other people[8]

Source: City of Toronto. Healthy Aging in Toronto. March 2017.

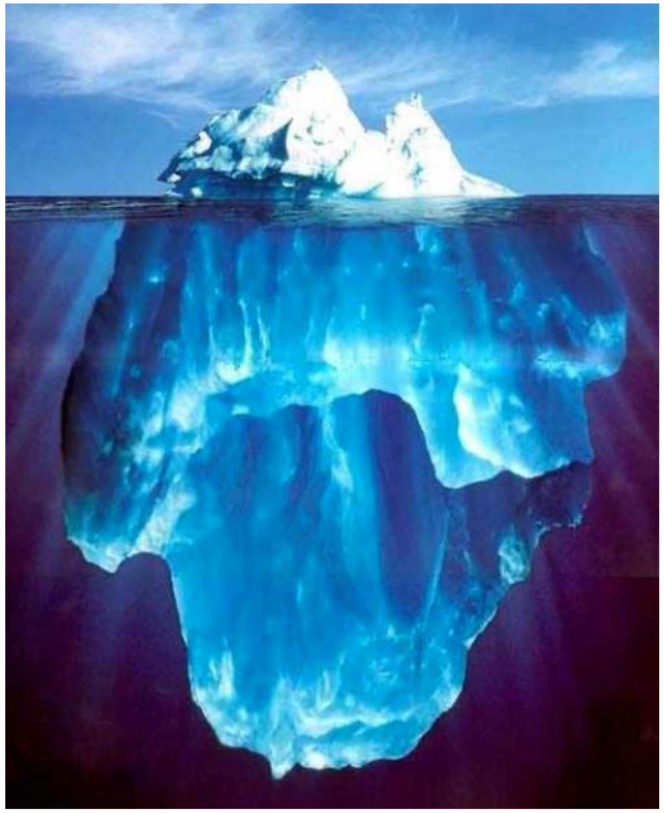
Complicating Factor: Rise of Dementia



Source: Morton-Change F, Williams AP et al., Towards a community-based dementia care strategy: how do we get there from here? HealthcarePapers. vol. 16, no. 2, 2016.

Challenge 4:
Caregivers Crucial, But Mostly "On Their Own"

- 'The backbone' of the home and community care sector
- In health care circles, some view them as a vast pool of 'free' labour that can help alleviate demand on the public health care system
- Despite this recognized importance
  - Caregivers remain the least researched health human resource category
  - 'Submerged iceberg' – Colombo et al 2011



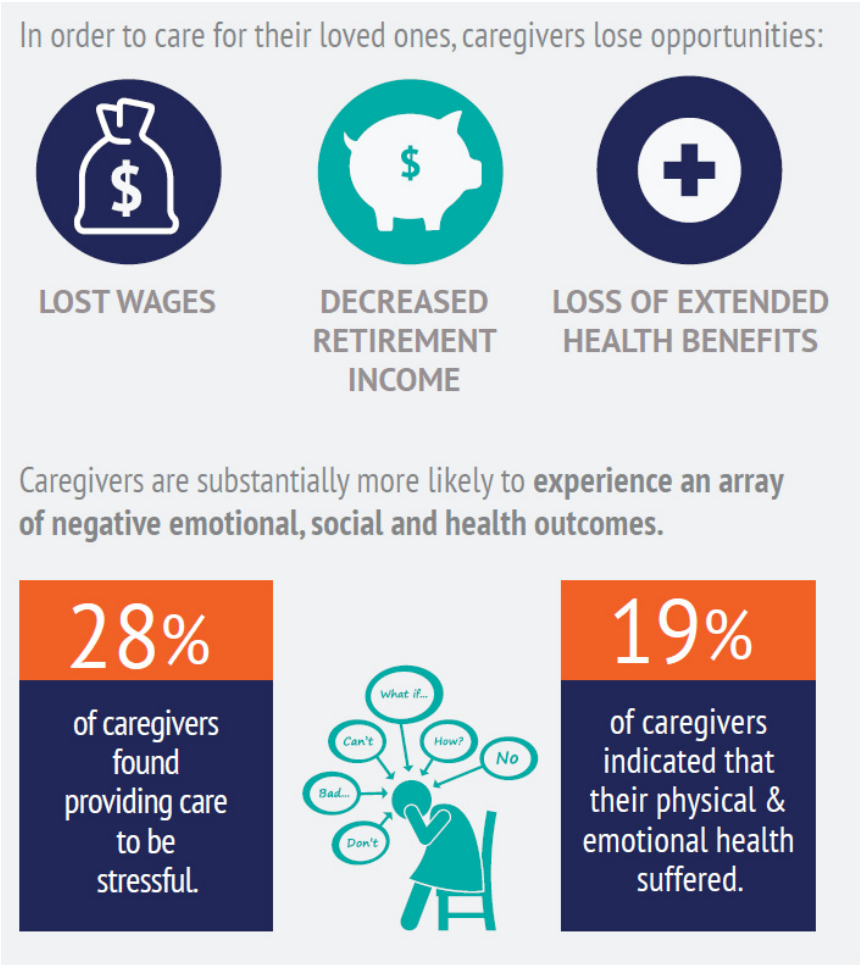
Source: Lilly M. Who really cares? Caregiving intensity, labour supply and policymaking in Canada. 2011.
http://queensu.ca/sps/sites/webpublish.queensu.ca.spswww/files/files/Events/Conferences/QIISP/2011/meredith_lilly.pdf

Caregivers: Growing Burden of Care

- Greater burden of more complex, continuing care shifting to caregivers
  - Rise of dementia and other chronic needs
  - Decline of “before-the-fact” home care
  - Push to move people out of hospitals “quicker, sicker”
- More caregivers taking on controlled acts
  - Suctioning, catheters, oxygen, feeding tubes, medication
  - Even controlled acts may be exempt if “routine activity of daily living”

Source: Williams, Peckham et al., Caring for Caregivers: challenging the assumptions. HealthcarePapers vol. 15, no. 1, 2015.

Caregiving: Costs and Consequences



Source: Canadian Caregiver Coalition. http://www.ccc-ccan.ca/

Challenge 5:
Rural and Remote Health Largely Uncharted

- Beyond city limits, challenges mount
  - Demand side
    - Rapidly aging populations
      - Older persons living longer; younger persons leaving earlier
    - Greater likelihood of multiple chronic health and social needs
  - Supply side
    - Low critical mass in small communities
    - Sparse formal community-based care
    - Fewer caregivers

Outcome: Default to Beds

- Greater likelihood of default to hospital and residential LTC beds in cities
  - Indigenous elders placed in non-indigenous settings away from their communities

Part 2: Where We Want to Go

Supporting People "Closer to Home"

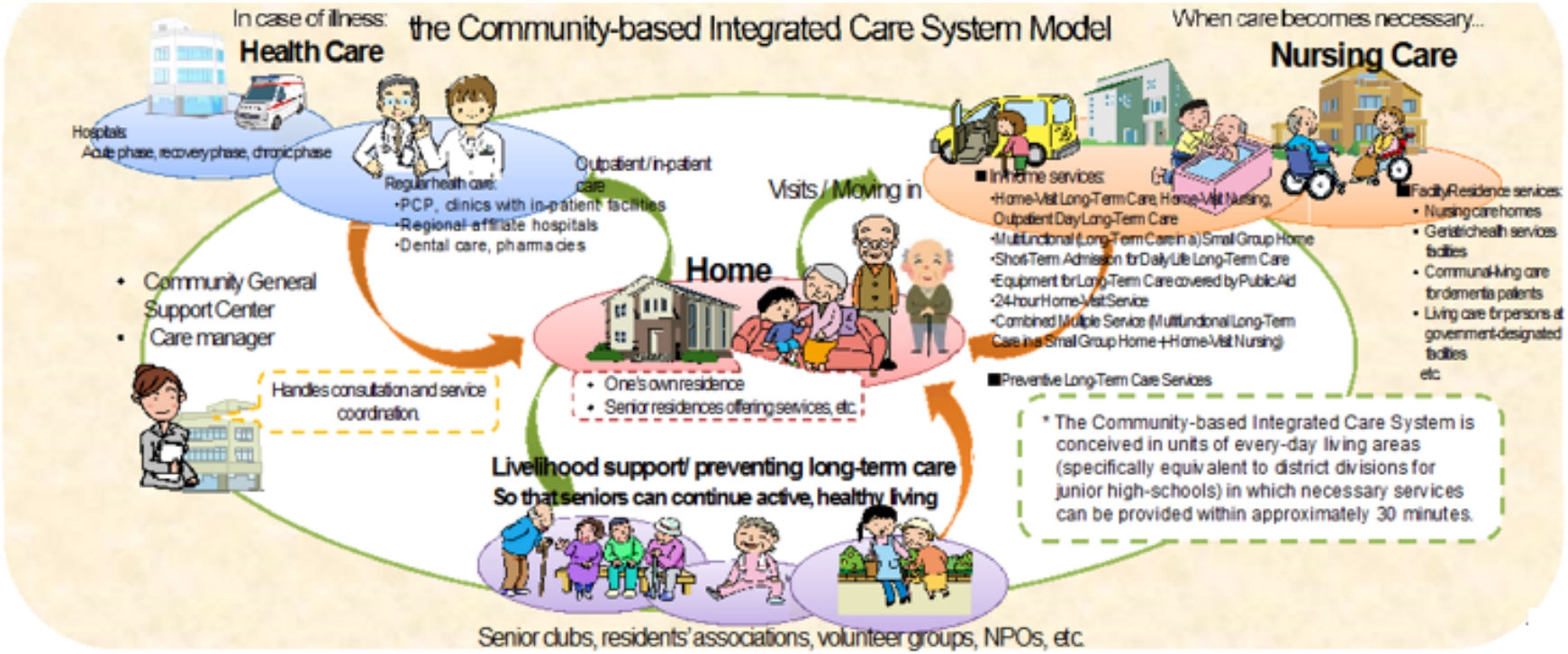
The Better Way:

Toward a Person-Centred Continuum of Places for Care Over the Longer Term

- Health Services Restructuring Commission (1996-2000)
  - Authority to close or merge hospitals
  - Advise (only) on community reinvestments
- Experts concluded:
  - Create a continuum of residential "beds" as well as equivalent "places" in supportive housing, adult day programs, at home
  - Emphasize "downward substitution" to the "least restrictive, least intrusive setting possible"
  - Support families "in their role as caregivers"
  - "Funding levels … determined in relation to the needs of the resident, not the location of care" (HayGroup, 1997)

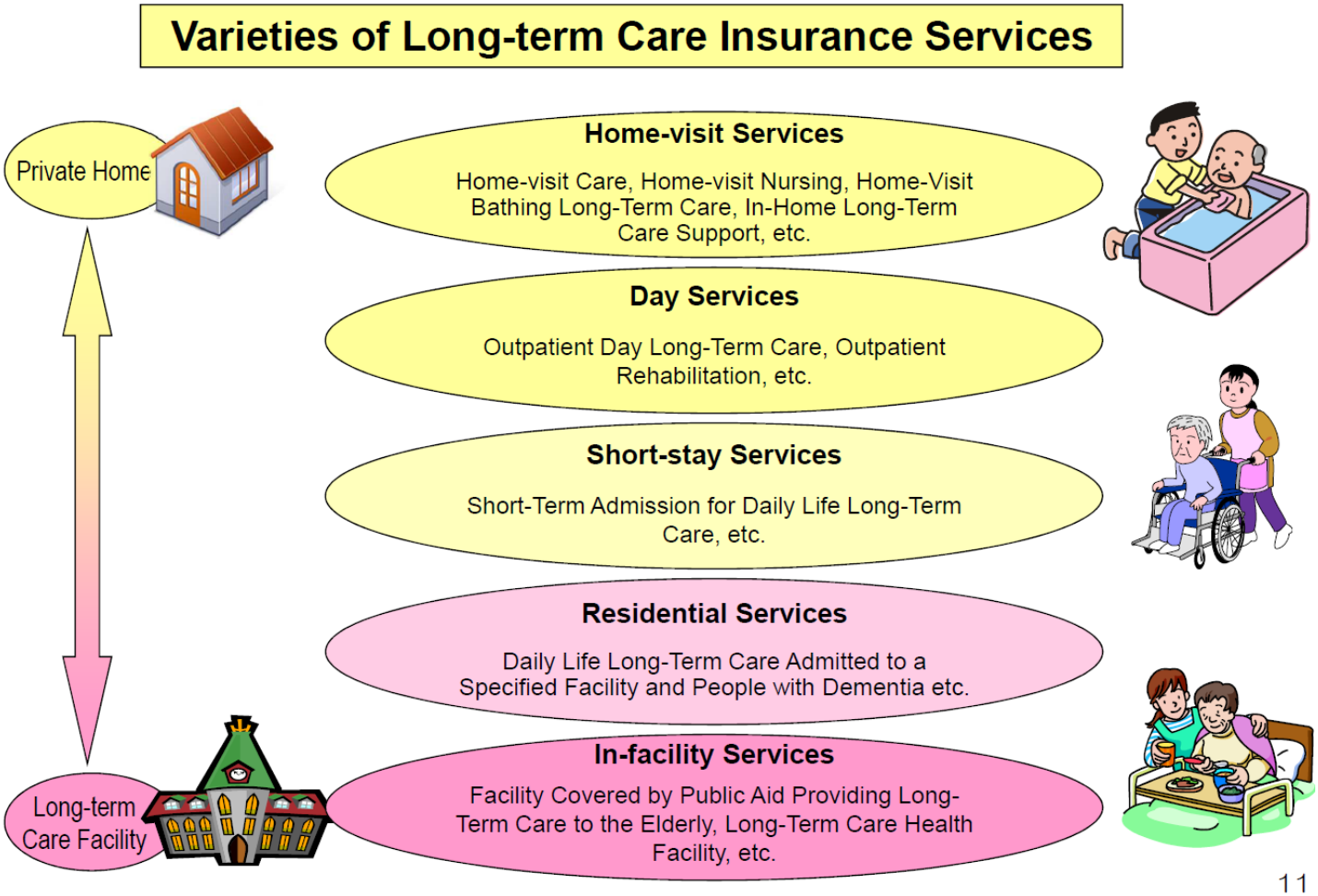
Innovations 1:

Japan's Plan for Integrated Long Term Care by 2025



Source: Ministry of Health, Labour and Welfare. Long-Term Care Insurance System of Japan. 2016.
http://www.mhlw.go.jp/english/policy/care-welfare/care-welfare-elderly/dl/ltcisj_e.pdf

Japan's Long-Term Care System:
Integrated Levels of Funding, Individualized Care



Building Places "From the Ground Up":
Japan's Dementia Open Houses

- Run by volunteers who offer people with dementia and carers access to all-day support in private homes
  - Small grants
  - Volunteer training
  - Caregiver peer support
  - 24/7 help line
  - "Light touch" regulation

Source: http://www.ryerson.ca/content/dam/crncc/enews/pdfs/2015/2015-fall-winter-crncc-enews-vol35.pdf & http://www.housinglin.org.uk/_library/Resources/Housing/Practice_examples/Housing_LIN_case_studies/HLIN_CaseStudy_105_Japan-Grassroots.pdf

Normalizing Needs:

Restaurant of Order Mistakes

"Cafe's and drop-in centres are up and running. Local businesses are spreading awareness and stickers are available, with QR codes on them, that can be easily worn on clothes… police officers can just scan the code and immediately there's that person's details."

Source: Braik-Scrivyer. Dementia Lessons from Japan. https://www.dementiacafe.co.uk/dementia-lessons-japan/

Innovations 2:
Program of All-Inclusive Care for the Elderly (PACE)

- International "gold standard" of integrated care for "high needs" older persons
  - 90+ replications in 29 states
  - People to care: clients transported to day centre
  - Full access to a comprehensive suite of primary care, specialty care, medications, transportation, meals, dental & vision services, mental health, emergency care
  - Inter-disciplinary teams (including bus drivers) assess & manage needs

Source: Commonwealth Fund. 2016. http://www.commonwealthfund.org/publications/case-studies/2016/aug/on-lok. Also, On Lok PACEpartners. http://pacepartners.net/what-is-pace/

On Lok Lifeways: San Francisco PACE Model

- All clients nursing home eligible
  - Average age of 83, 16+ medical conditions, many with cognitive impairments
- Per diem state funding at 95% of nursing home cost
- On Lok responsible for *all care*
- Strong incentive to find the most appropriate care options to maximize wellbeing and independence

On Lok Lifeways:

Evidence-Based Outcomes

- People
  - Better health status and quality of life, lower mortality, increased choice, greater confidence
- Services
  - More prevention and maintenance: only 25% of budget spent on hospitals, x-rays, lab tests, medications, medical specialists
- Costs
  - 21% lower overall than for other adults with similar needs

Source: Commonwealth Fund. 2016. http://www.commonwealthfund.org/publications/case-studies/2016/aug/on-lok

Rural PACE "Hub & Spoke:"

Building Critical Mass

- Urban hub (Bismarck)/rural site (Dickinson)
  - PACE day centre & clinic attached to a nursing home
  - Shared administrative costs and infrastructure
    - Dickinson site can support a small rural population (130 participants) cost-effectively
  - Strengthened capacity to offer interdisciplinary care
    - Doctors, nurses, social workers, therapists, home care attendants, day/health center workers, transportation coordinators, dietitians, recreational staff, and van drivers

Source: Rural Health Information Hub. Northlands PACE. https://www.ruralhealthinfo.org/community-health/project-examples/776

Rural PACE "Hub and Spoke:"

Creating Supportive Networks

- Day Centres in 2 small towns (Eckert and Montrose) and a satellite (Paonia) in Colorado
  - Medical & hospital services, therapy, mental health, home modifications, supports for daily living, meals, transportation, hospice, lab services, 24 hour service to on-call nursing, caregiver supports
  - Interdisciplinary team: physicians, nurses, therapists, dieticians, drivers, social workers, recreational specialists
  - Partnerships with volunteers, disability organizations, county offices, health and human services agencies

Source: Rural Health Information Hub. Senior CommUnity Care.
https://www.ruralhealthinfo.org/community-health/project-examples/784

Innovations 3: VON Seniors Managing Independent Living Easily (SMILE), South-East Ontario

- Serves "at risk" frail older persons *and* "at risk" caregivers *in urban and rural areas*
  - Growing numbers of older persons with assessed needs comparable to long-stay home care clients and LTC-wait listed clients
- Similar to Veterans Independence Program (VIP)
  - Canada's national home care program for vets

Source: SMILE. http://www.von.ca/en/hastings/service/seniors-managing-independent-life-easily-smile

SMILE: Supported Self-Management

- Specially trained care managers equipped with dedicated client budgets support person-centred decision-making
  - Partners co-create individualized care plans taking into account budgets and mix of local resources
    - Identify & prioritize needs, preferences & goals
    - Access most appropriate mix of resources
    - Provide continuing care navigation and coordination
    - Monitor outcomes

SMILE: Mobilizing Informal & Formal Capacity

- Local resources may include:
  - "Traditional" community-based services & supports
    - Meals-on-wheels, homemaking, transportation, respite, foot care, assistance with shopping
  - "Non-traditional" supports from neighbours, friends, volunteer groups
    - Home maintenance, grocery shopping, meals, transportation, snow shovelling provided by friends, neighbors, volunteers, clubs, schools

Part 3: Bottom Line

Toward a Person-Centred Continuum of Care Places

Bottom Line: *Person-Centred Care Places*

- Governments have an important role to play
  - Enabling policy frameworks with clear goals crucial
- Actively engage care recipients, caregivers, care providers and communities
  - What's most important to care recipients, caregivers and communities?
  - What traditional and non-traditional resources are (or could be) available to support independence and quality of life in urban and rural/remote settings?

Take-Away: Essentials

- Look beyond conventional health care services
  - Include everyday essentials like transportation, social engagement, housing, home maintenance, medications checks, meals, banking
  - Interdisciplinary care teams
- Build a person-centred continuum of care places
  - “Downward” substitution to the least restrictive care setting

Take-Away: Essentials

- Acknowledge and support informal caregivers
  - Current & future caregivers
  - Social support networks & communities
- Fund based on care needs, not location of care
  - Accountability for care, not just services
  - If governments willing to pay for care beds, why not pay the same amount to help persons stay in their own homes and communities?

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