

From Surviving to Thriving: Younger Adults in Long Term Care Summary of Findings

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THE ISSUE

- There is a lack of appropriate alternatives for housing and care for adults (18-65) with disabilities
- Family/friend caregivers can not always provide care needed at home.
- Many people who are not seniors live in long-term care (LTC) environments primarily designed to meet the needs of older adults
- Many LTC facilities are not ideally suited to meeting the needs of younger residents

Canadian Healthcare Association. (2009). *New directions for facility-based long term care Nouvelle direction pour les soins de longue durée en établissement*. Ottawa, Ont.: CHA Press. Retrieved from <http://www.deslibris.ca/ID/219593>

Muenchberger, H., Sunderland, N., Kendall, E., & Quinn, H. (2011). A long way to Tipperary? Young people with complex health conditions living in residential aged care: a metaphorical map for understanding the call for change. *Disability & Rehabilitation*, 33(13/14), 1190–1202.

THE ISSUE CONTINUED

- Younger LTC residents want to thrive – take part in productive and meaningful activities (e.g. work, volunteering, education, leisure)
- What are the opportunities for and barriers to productive and meaningful activity for younger LTC residents?
- This is an understudied issue – more evidence is needed to inform further research, policy, and LTC practice

PURPOSE OF THE STUDY

1. Develop a summary quantitative profile of younger Nova Scotia long-term care residents by analyzing provincial data about their characteristics from interRAI survey data collected upon admission
2. Complete qualitative case studies of examples of housing and supports that have successfully engaged younger adults in productive and meaningful activities
3. Review and synthesize research and other reports
4. Use this evidence to inform the development of further research

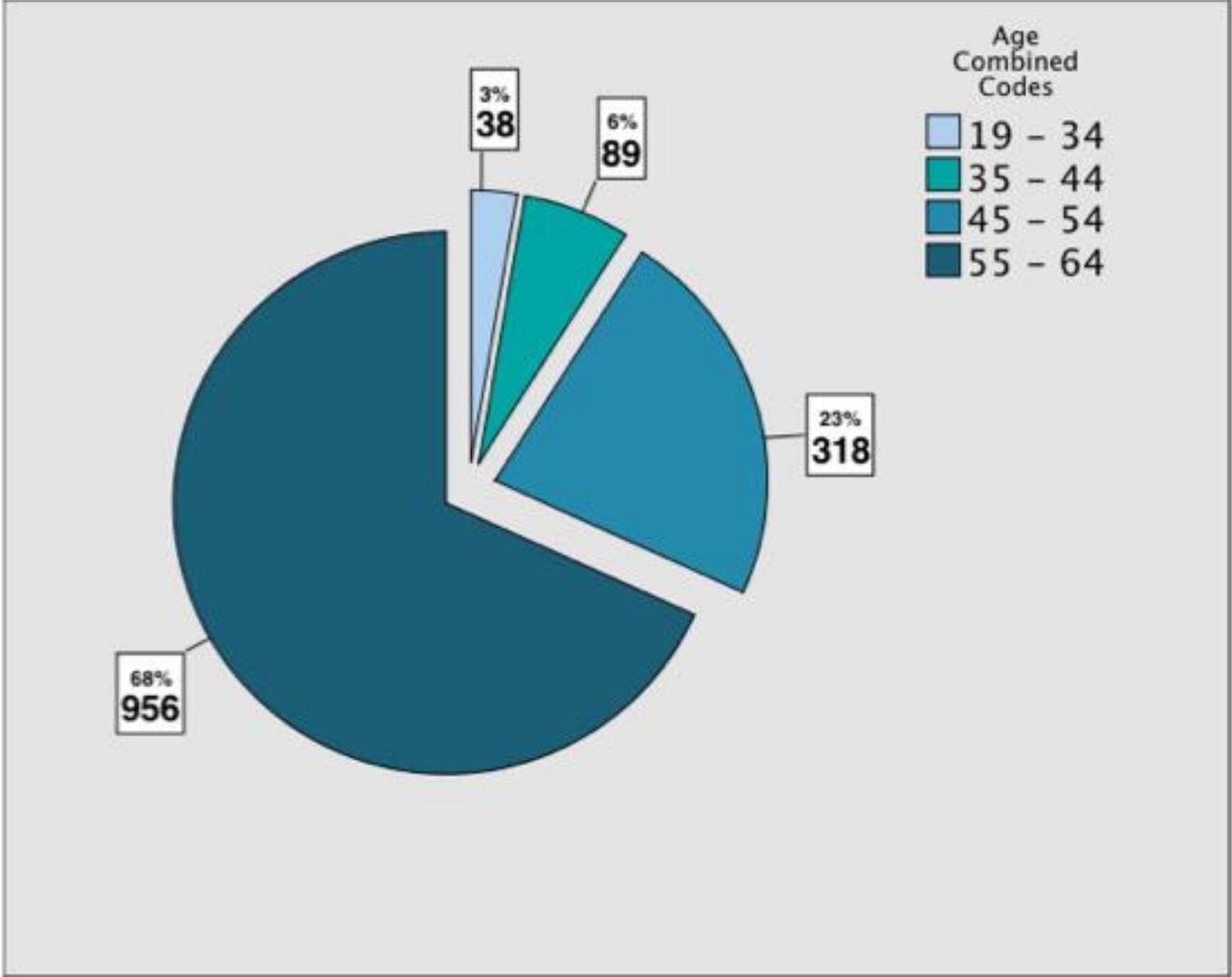
QUANTITATIVE RESEARCH OBJECTIVES – Led by Dr. Marie Earl

- Develop a summary profile of younger adults who live in Nova Scotia residential LTC homes using their pre-admission assessment data
- Analyze provincial data about their age, gender, income, reasons for admission, geographic location, and other characteristics available

METHODS

- secondary analysis of designated variables from the admissions assessment (SEAscape database, NS DHW)
- 1401 Nova Scotia clients admitted to LTC, aged 19-64 at time of assessment from January, 2007 – December, 2016
- variables were categorized according to
 - the World Health Organization International Classification of Function (World Health Organization, 2001)
 - the Social Determinants of Health (Public Health Agency of Canada)

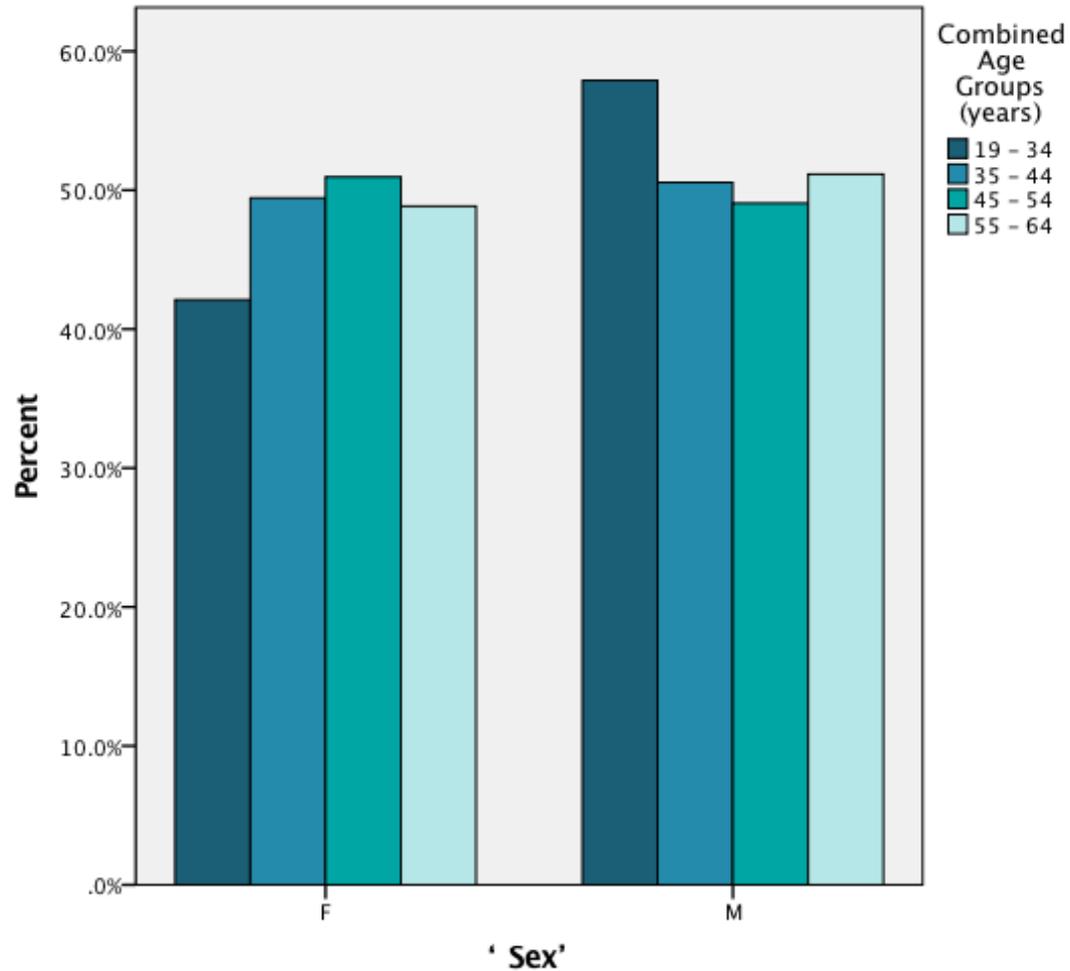
AGE DISTRIBUTION



GENDER

≈50% of all clients were identified as Female

≈ 42% Female, and ≈ 58% Male among youngest clients



COMPARISONS WITHIN “PERSONAL” DOMAIN

Youngest Cohort (19-34 yrs)	Oldest Cohort (55-64 yrs)
Gender (SD) • M:F \cong 58%: 42%	• M:F \cong 51%: 49%
Education (SD) \cong 33% High School; 33% post-secondary	\cong 10% High School; 30% post-secondary
Marital Status \cong 90% never married	\cong 35% never married
Personal Health Practices & coping skills (SD) <ul style="list-style-type: none"> • Activity - too little; • Some alcohol or tobacco use; • Diet - ?poor 	<ul style="list-style-type: none"> • Activity - too little • Some alcohol or tobacco use; • Diet - ?poor
Health conditions \cong 30% assessed in hospital \cong 68% Chronic Condition: CP, Hemiplegia Head Trauma)	Health conditions \cong 45% assessed in hospital; < 5% end-of-life \cong 97% Chronic Condition(s): Stroke; CAD, PVD; dementia; psych; respiratory; thyroid; diabetes; arthritis

PHYSICAL FUNCTIONING - ADL

- Assistance needs varied; some age trends present , independence more common among older clients

≅50% of youngest clients required total assistance with

- Dressing (Upper body; lower body)
- Bathing
- Personal hygiene
- Toilet use

≅25% of youngest clients required total assistance with eating

PHYSICAL FUNCTIONING – IADL

≅ 80% of clients required total assistance with

- Meal preparation
- Ordinary housework
- Shopping (either performed by others, or did not occur)

≅ 70% of clients required total assistance with

- Transportation (either performed by others, or did not occur)

≅ 60% of clients required total assistance with

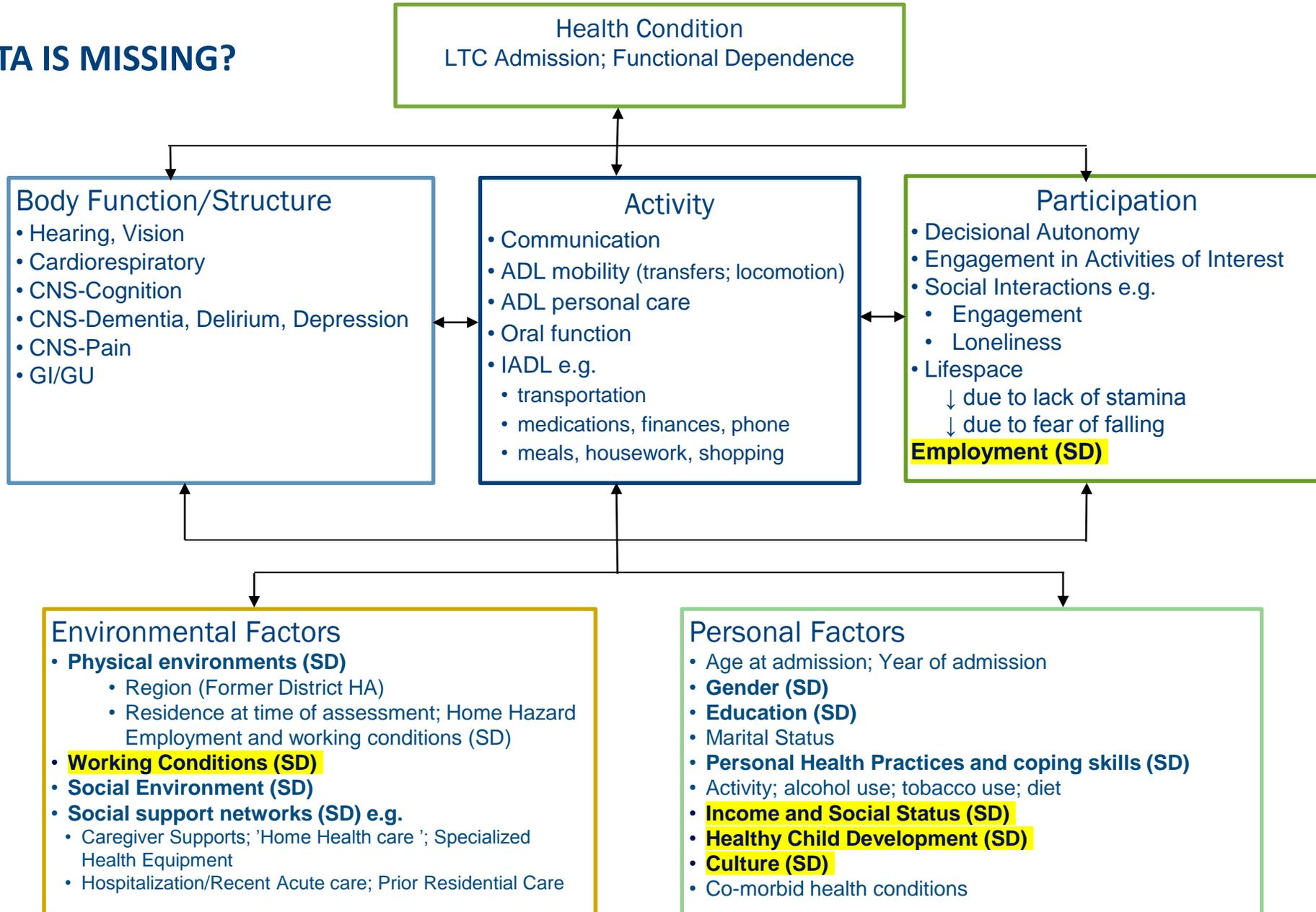
- finances
- managing medications
- phone use (either performed by others, or did not use)

COMPARISONS WITHIN “ENVIRONMENTAL” DOMAIN

Youngest Cohort (19-34 yrs)	Oldest Cohort (55-64 yrs)
Physical environments (SD) ≅ 50% Central Region; ≅ 65% Residing private home, no home care; ≅ 10% restraint; few fall hazards; ≅10% access issues;	Physical environments (SD) ≅ 40% Central Region; ≅ 65% Residing private home, no home care; < 5% abuse/restraint; few fall hazards; ≅ 8% access issues
Social Environment (SD) ≅ 85% living with family member caregivers	Social Environment (SD) ≅ 40% living alone
Social support networks (SD) e.g. ≅ Caregiver Supports at full capacity; ≅ Very little Home Health care (Nursing, PT, OT, Speech); ≅ 50% full support f (O ₂ ,IV, Catheter)	Social support networks (SD) e.g. ≅ Caregiver Supports at full capacity; ≅ Very little Home Health care (Nursing, PT, OT, Speech); ≅ 60% full support (O ₂ ,IV, Catheter)

WHO ICF Model, with Social Determinants of Health

WHAT DATA IS MISSING?



POINTS TO PONDER

The Profile

- **Wide range of ages, with small proportion of adults younger than 35 yrs**
- **Age groups similar in some ICF domains e.g.**
 - **limited access to outpatient/home-care health care; caregiver capacity**
 - **transportation problems**
 - **limited mobility and other ADLs**
- **Age groups differ in some ICF domains e.g.**
 - **Health Diagnoses, and perceived health status**
 - **Family-members as care givers**

POINTS TO PONDER

The “Admissions” Profile - Gaps

- Lacking Social Determinants of Health
 - Income and Social Status
 - Education and Literacy (Literacy)
 - Employment/Working Conditions
 - Healthy Child Development
 - Biology and Genetic Endowment
 - Gender (Gender Identity)
 - Culture
- Exploratory analyses of systematic relationships among factors
- Comparisons with profiles of those assessed and not placed in residential LTC

POINTS TO PONDER

Potential Implications for Services

- **Services prior to residential LTC admission, and within residential LTC e.g.**
 - **protect or restore function (physical and cognitive)**
 - **supports for meaningful “Participation”**
 - **client-centered assessments and interventions e.g.**
 - **? minimize participation restrictions**
 - **? culturally appropriate/competent services**
 - **? impact of socioeconomic status on admission**
 - **? impact of child development on admission**

QUALITATIVE RESEARCH



QUALITATIVE RESEARCH - Led by Dr. Katie Aubrecht

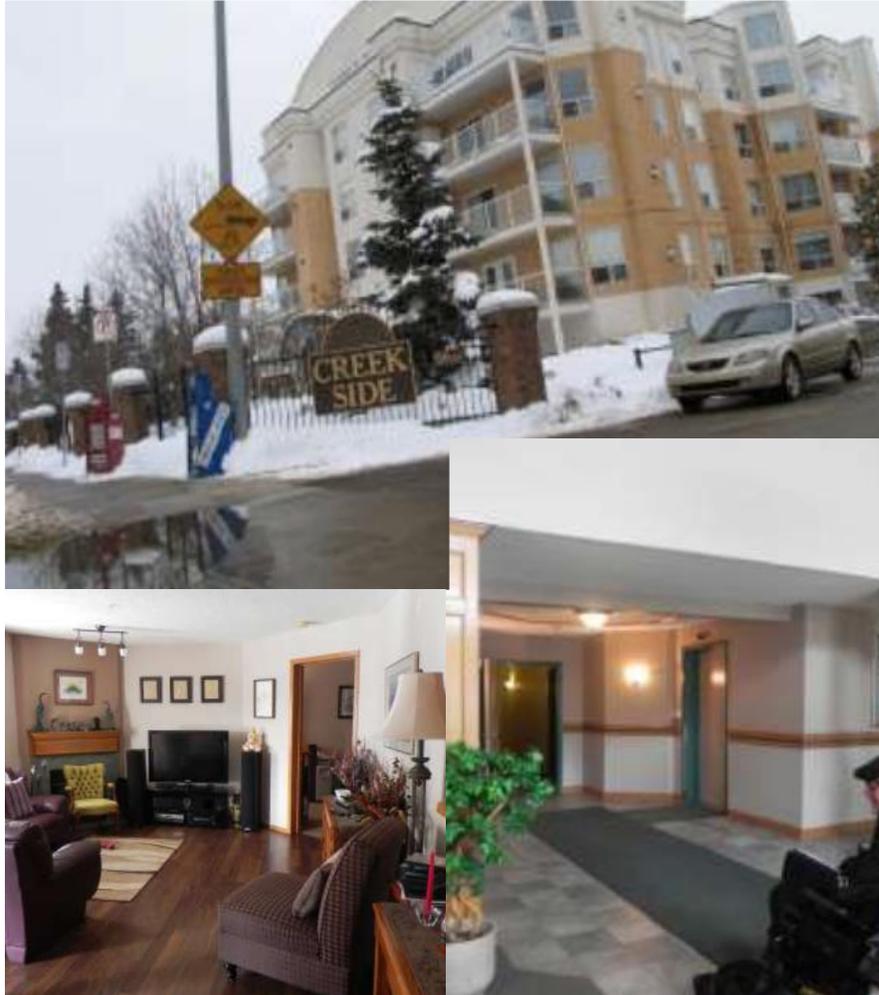
- Qualitative Interviews – 2 cases, Edmonton & 1 case, Boston
- LTC Facilities/Programs with Purposeful Design for Younger Adults
- Younger Adults with disabilities were part of the research team
- Interpretive, Qualitative Cases incl. Multiple Perspectives

QUALITATIVE RESEARCH OBJECTIVES

- Complete case studies to explore examples of housing and supports that have successfully engaged younger adults in productive and meaningful activities
- Explore research design techniques that integrate younger adult residents of LTC as co-researchers and experts on the team

NURSING HOME RESIDENT RESEARCHERS

- Resident engagement in research co-design, data collection, coding and analysis
 - Resident-centred approach to research
 - resident perspective built into the research process
 - mechanism to ensure relevance of findings to younger residents
- Research structure and approach aligned with Social Determinants of Health Approach
 - Emphasis on meaningful activities – education, training and paid work
 - qualitative research training for resident researchers
 - research activities = compensated labour



Case #1 Creekside

- Edmonton, Alberta
- non-profit, mixed-residence condominium (no children)
- residents are property owners and Board members (can also rent)
- care coordinator is building facilities manager
- care attendants support social, education, training and labour force participation
- aging in place
- to qualify, residents must be self-directed, and socially engaged

Case #2 Capital Care Dickinsfield



Other Programs Involving Young Adults:

- Adult Duplexes (supportive living group homes, 18+)
- McConnell Place North (cottage model/focus on dementia)



- Northeast Edmonton, Alberta
- 257 LTC Beds
- Pool, gym, OT, PT, Recreation, Music Therapist and access to hospital
- Specialized Young Adult Program
 - Age 18-59
 - 80 beds

Case #3 The Boston Home



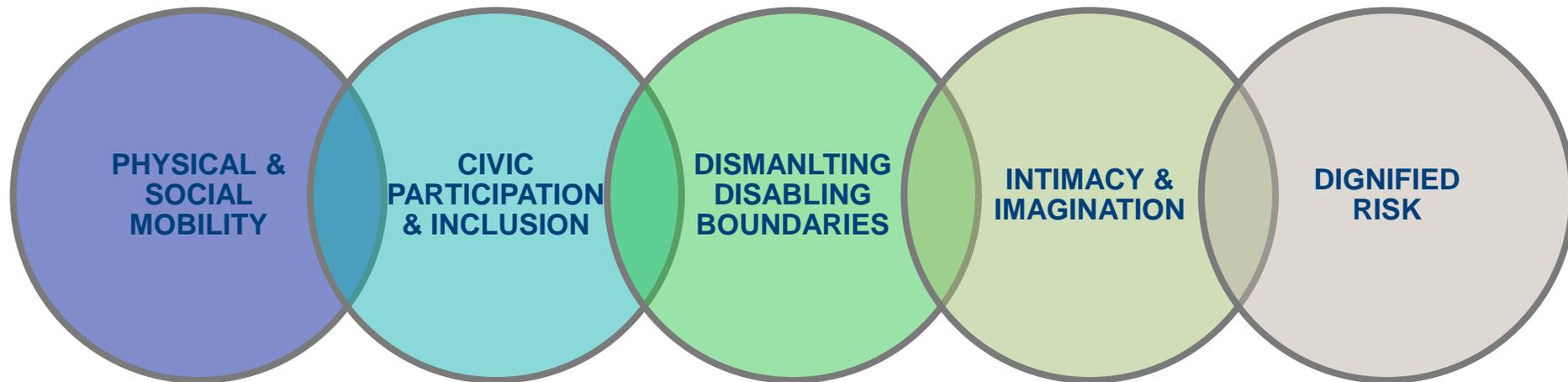
- Boston, MA, US
- Founded 1881
- 96 residents + day program clients
- Total staff employed (incl. admin) = 200
- Avg. resident aged 58yrs (> 4yrs, 2010)
- Clinical Profile: Adults with progressive neurological diseases (advanced Multiple Sclerosis)
- B.FIT! Outpatient Respite & Wellness Program
- University Partnership (MIT)
- Mixed residence care community (Apartments)

ANALYSIS

- **Thematic analysis** (Braun & Clark, 2006)
- **Contextualist method**
 - reflect and unpack realities of young adults residing in LTC environments
- **Social Determinants of Health (SDH) lens**
 - Coding shaped by interest in understanding meaningful and productive participation for diverse cohort with complex care and social needs

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.

THEMES



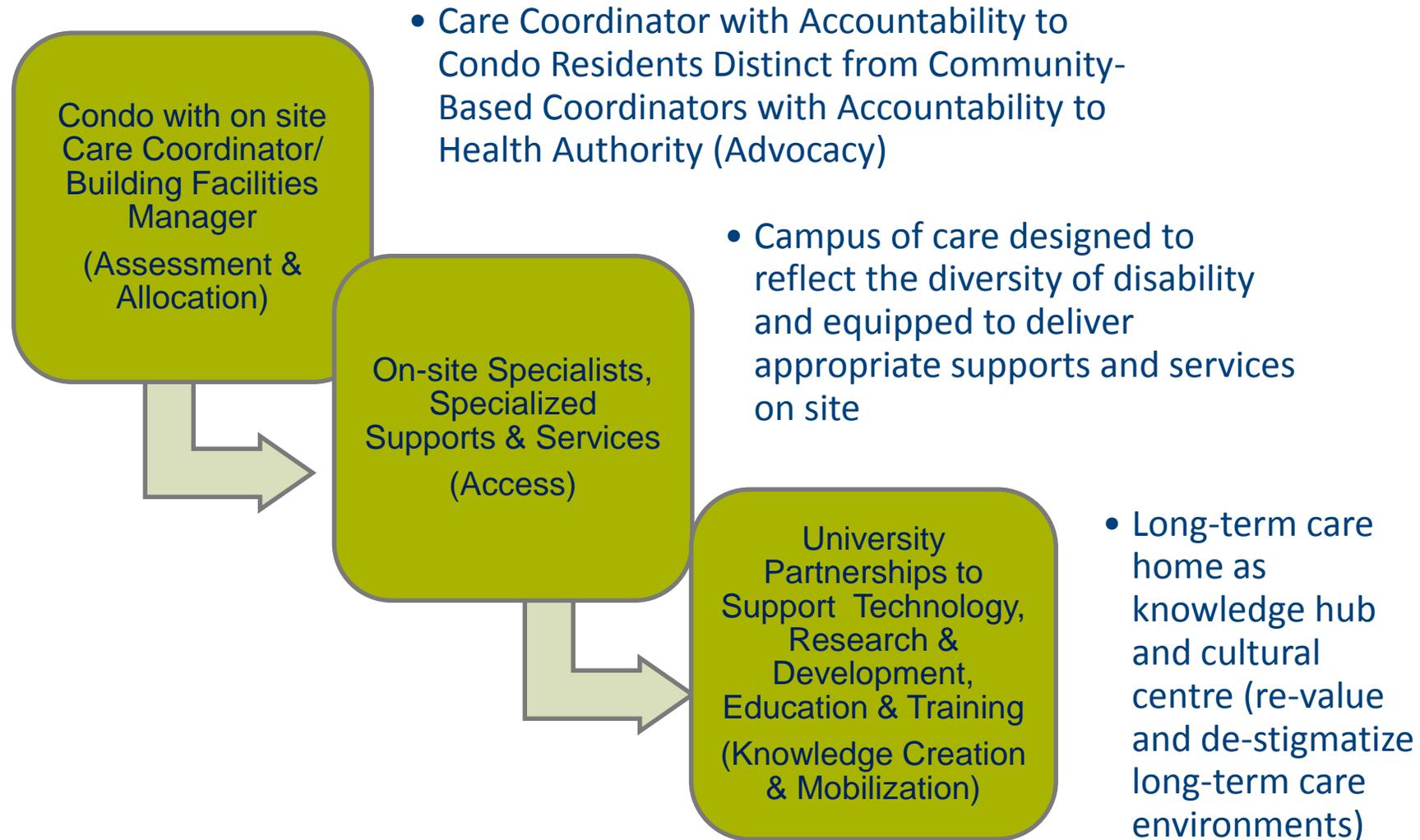
PHYSICAL & SOCIAL MOBILITY, CIVIC PARTICIPATION & INCLUSION and DISMANTLING DISABLING BOUNDARIES

- All promising cases were in urban environments with **ACCESSIBLE PUBLIC TRANSIT**
- Supports to do activities **OUTSIDE OF HOME** and have family/friends be present and engaged in everyday life **IN HOME** were highlighted as important by multiple perspectives
- At Creekside and Boston Home **STAFF ACCOMPANY RESIDENTS OFF-SITE** to school, work, familial and social events
- Residents emphasized the importance of **TECHNOLOGY** in being able to work, pursue **TRAINING AND EDUCATION**, and remain **SOCIALLY ENGAGED**

INTIMACY & IMAGINATION and DIGNIFIED RISK

- Cases provided supports for people with diverse embodiments and different levels of care needs
 - **PHYSICAL ENVIRONMENTS THAT SUPPORT POWER WHEELCHAIRS** viewed as critical for younger adults with complex care situations
- Disability not a barrier to intimacy, we need **IMAGINATION**
 - Opportunities for shared residence with intimate others
 - Technology and trained care providers support intimate relations (lift, nurses)
 - Friendships
- Need **CREATIVE APPROACHES, INTELLIGENT PLANNING AND INVESTING, AND FISCAL MANAGEMENT** which capitalized on existing resources and adapted to residents' needs and preferences

3 Models of Purposeful Care



CONCLUSIONS

- **We were able to learn a great deal about the characteristics of younger residents in long-term care in Nova Scotia.**
- **We also gained additional insights into the experiences of those living in various types of care facilities included in the cases.**
- **The three resident researchers were involved throughout this entire study, and this added strength to our study.**
- **The results will be used by the team in identifying the development of additional research, such as the development of more appropriate intake assessment tools for younger residents in long-term care.**

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