Successful Aging – *Evaluating the effect of action on frailty*

A Report submitted to Reena
and Mary Centre

June 25, 2019

Hélène Ouellette-Kuntz, PhD
Lynn Martin, PhD
Tori Barabash, MSc (candidate)
Eve Deck, MPH

MAPS
MULTIDIMENSIONAL ASSESSMENT
OF PROVIDERS AND SYSTEMS

Executive Summary

Previous work has shown that frailty is modifiable – individuals with intellectual and developmental disabilities (IDD) may transition from non-frail to pre-frail or frail, pre-frail to frail or non-frail, and from frail to pre-frail or non-frail. As frailty involves multiple deficits across multiple domains, intersectoral collaboration is needed to review existing supports and services, and to identify different or new supports needed specific to frailty. The intersectoral team advocates, coordinates and manages supports and care, and follows up on plans to ensure these are implemented and continue to be responsive to new and emerging needs.

In this project, pilot testing the Home Care-Intellectual and Developmental Disabilities Frailty Index (HC-IDD FI) was undertaken in order to determine how knowledge of an individual with IDD's frailty status would affect care planning decisions, and whether such decisions would result in changes in frailty. Care planning by designated coordinators within the developmental services (DS) sector was examined with a focus on how they collaborated with the home care sector to meet the needs of individuals with IDD 40 years and older identified as frail or pre-frail.

The findings suggest that when issues related to frailty are identified, this knowledge leads to actions that have the potential to improve the individual's status and functioning over time. Issues related to physiological (such as functioning, physical health, continence) and social (such as loneliness, participation in activities) were identified by both the home care and DS sectors; the former was more commonly acted upon by home care while the latter was more often addressed by the DS sector. Positive change in these domains – and others, were noted when providers targeted identified issues in their care plans. However, some decline was noted, particularly in the physiological domain. Overall, it can be said that identification of frailty and related deficits resulted in improved outcomes.

Coordinators in the DS sector developed a care plan template that allowed them to document frailty-related areas of concern and associated actions and outcomes. Given that the frailty deficits stem from the home care assessment, there is a need to develop agreements between the home care and DS sectors to share assessment information – in fact, this happened toward the end of the project. Shared access to assessment and care planning documents will help to increase consistency and quality of information, and reduce duplication; it will also help to better define the roles of home care and DS providers with respect to the various issues to be addressed to support people who are frail in the community.

Three recommendations to further assist the home care and DS sectors to support adults with IDD who are frail in the community stem from this project:

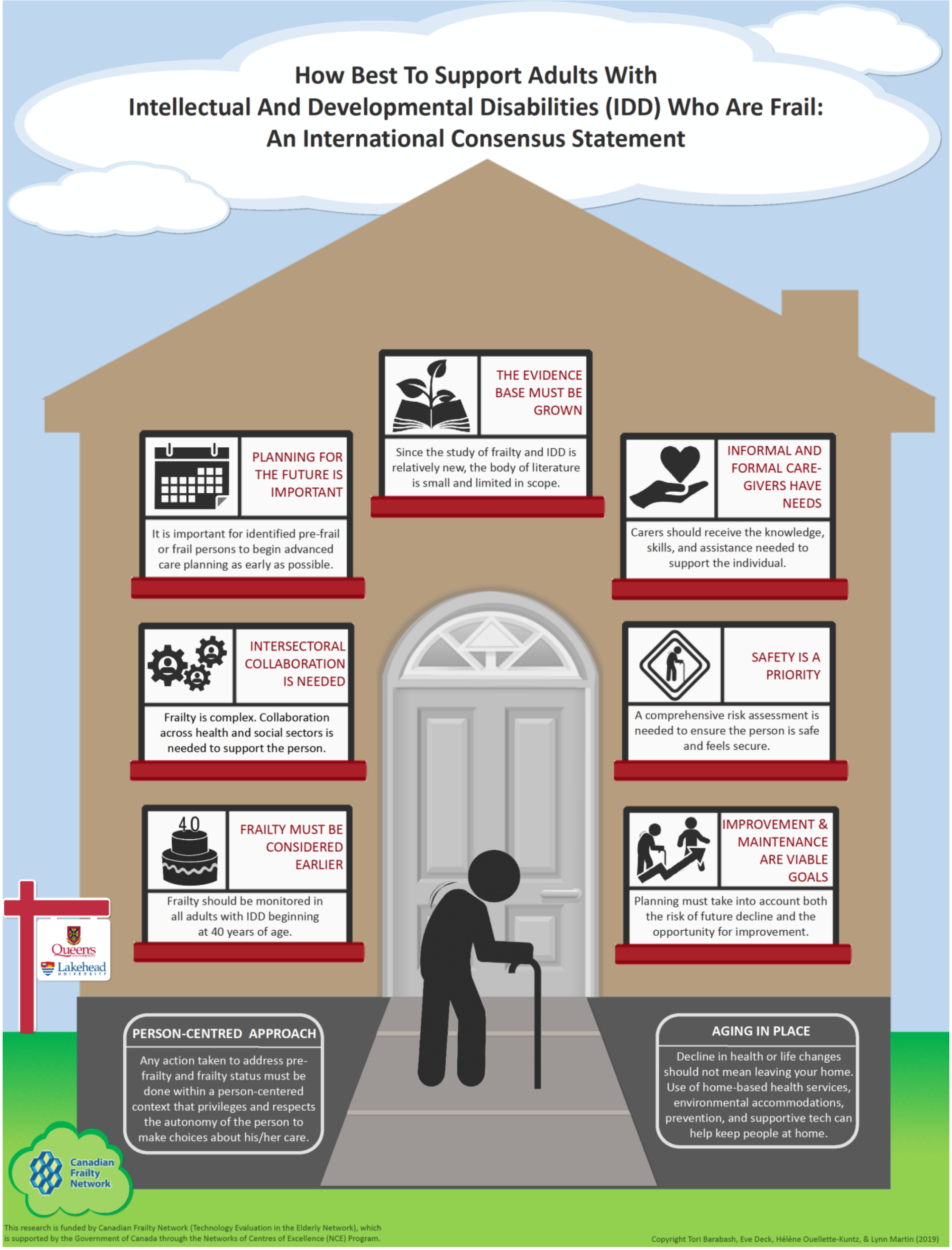
1) Training to build capacity in the DS sector related to frailty
2) Development of a formal data sharing agreement
3) Development of intersectoral collaboration protocols

Introduction

In light of the increasing life expectancy and growing segment of the population with intellectual and developmental disabilities (IDD) who are aging in the community, Reena and Mary Centre undertook several activities to enhance the inclusion of older adults with IDD into senior services. The 24-month project was funded by the province's Ministry of Community and Social Services (2017-2019 Modernization Grant). The project "Successful Aging – Frailty, Transition and Inclusion into Senior Services" included updating the "Aging with a Developmental Disability – Transition Guide for Caregivers" (Ontario Partnership on Aging and Developmental Disabilities, 2005), pilot testing the Home Care-Intellectual and Developmental Disabilities Frailty Index (HC-IDD FI; McKenzie, Ouellette-Kuntz, & Martin, 2015), and evaluating the effect of designated care coordinators. This report describes the latter two activities.

Pilot testing the HC-IDD FI was undertaken in order to determine how knowledge of an individual with IDD's frailty status would affect care planning decisions and whether such decisions would result in changes in frailty. Frailty status at baseline was based on the IDD HC FI, a frailty index specifically designed for adults with intellectual and developmental disabilities that was developed using an accumulation of deficits approach and validated using data from the RAI-HC. The index is composed of 42 items in the RAI-HC related to physiological, cognitive, psychological, and social deficits, as well as service needs. The frailty score is calculated by dividing the deficit score by the total number of deficits assessed. Based on scores, individuals are considered to be non-frail (score ≤0.21), pre-frail (0.21<score≤0.3), or frail (score>0.30). Previous work has shown that frailty is modifiable – individuals with IDD may transition from non-frail to pre-frail or frail, pre-frail to frail or non-frail, and from frail to pre-frail or non-frail (Martin, McKenzie & Ouellette-Kuntz, 2018). However, there is no evidence to support the use of specific interventions to support adults with IDD who are pre-frail or frail. To address this gap, a consensus statement was recently published that provides principles and recommendations on which to base actions related to frailty among adults with IDD (Ouellette-Kuntz et al., 2019); see Figure 1. This project uses the consensus statement as a basis for understanding care planning decisions and actions taken in response to knowledge of an individual's frailty status.

Measuring the effect of designated care coordinators in supporting adults with IDD who are frail or pre-frail focused on the third recommendation of the International Consensus Statement on Supporting Adults with IDD who are Frail; namely that inter-sectoral collaboration is needed. As frailty involves multiple deficits across multiple domains, a comprehensive and multidisciplinary approach to assessment of function, physical and mental health, behaviour, social context, decision-making, and supports is needed – with attention to how these interact. Intersectoral collaboration is also needed to review existing supports and services, and to identify different or new supports needed specific to frailty status. The intersectoral team advocates, coordinates and manages supports and care, and follows up on plans to ensure these are implemented and continue to be responsive to new and emerging needs. In this project, the care coordinators hired by Reena and Mary Centre led intersectoral planning efforts.



How Best To Support Adults With Intellectual And Developmental Disabilities (IDD) Who Are Frail: An International Consensus Statement

THE EVIDENCE BASE MUST BE GROWN

Since the study of frailty and IDD is relatively new, the body of literature is small and limited in scope.

PLANNING FOR THE FUTURE IS IMPORTANT

It is important for identified pre-frail or frail persons to begin advanced care planning as early as possible.

INFORMAL AND FORMAL CARE-GIVERS HAVE NEEDS

Carers should receive the knowledge, skills, and assistance needed to support the individual.

INTERSECTORAL COLLABORATION IS NEEDED

Frailty is complex. Collaboration across health and social sectors is needed to support the person.

SAFETY IS A PRIORITY

A comprehensive risk assessment is needed to ensure the person is safe and feels secure.

FRAILTY MUST BE CONSIDERED EARLIER

Frailty should be monitored in all adults with IDD beginning at 40 years of age.

IMPROVEMENT & MAINTENANCE ARE VIABLE GOALS

Planning must take into account both the risk of future decline and the opportunity for improvement.

PERSON-CENTRED APPROACH

Any action taken to address pre-frailty and frailty status must be done within a person-centered context that privileges and respects the autonomy of the person to make choices about his/her care.

AGING IN PLACE

Decline in health or life changes should not mean leaving your home. Use of home-based health services, environmental accommodations, prevention, and supportive tech can help keep people at home.

This research is funded by Canadian Frailty Network (Technology Evaluation in the Elderly Network), which is supported by the Government of Canada through the Networks of Centres of Excellence (NCE) Program.

Figure 1. Principles and recommendations for supporting individuals with IDD identified as pre-frail or frail.

The evaluation protocol

In 2017/2018, 102 clients of Reena and Mary Center 40 years of age or older were assessed by Central LHIN staff using the RAI-Home Care (RAI-HC)[1]. Based on these assessments, 26 were identified as frail or pre-frail (see Baseline report; Martin, Ouellette-Kuntz, & Choi, 2018).

Two Coordinators were hired to develop care plans for the 26 identified individuals, and coordinate their implementation. The coordinators' work on behalf of each client was documented for the 12 months following the initial assessment. The coordinators recorded contacts they had in order to develop and implement the care plan for each client using a communication log, and they developed and continually updated the care plan document. These documents detailed contacts with and services requested or received from professionals in the health sector (e.g., home care, nursing, occupational therapy, etc.) as well as in the community (e.g., fitness instructor). In addition to these client-specific documents, a summary of the project implementation was produced by the Project Manager to describe the coordinators' activities.

Follow-up assessments were completed by Central LHIN home care case managers one year after the initial assessment[1]. There was a change in the assessment tool used (from RAI-HC to interRAI-HC) midway through the current project resulting in most participants' follow-up assessment being with the interRAI-HC. Since not all 42 items from the IDD HC-FI were found in the interRAI-HC, a change in frailty status over the year could not be captured for all individuals.

Since one-year follow-up assessments were not completed for 3 individuals (e.g., death, move to long-term care facility), this report is based on 23 of the original 26 individuals identified as pre-frail or frail at baseline. The average age for the sample of 23 individuals was 63 years, with an equal number of individuals in the 45-64 and 65+ age groups (11 in each); one individual was under 45 years of age. Most were men (14 vs. 9 women), and had never been married.

The needs and planning focus for the 23 individuals identified by the home care and developmental services (DS) sectors are presented and contrasted. The planning that was undertaken by the DS coordinators is described with a focus on the intersectoral nature of the project. Outcomes after one year are then examined, incorporating data from both the home care and DS sectors. The report concludes with lessons learned and recommended next steps.

---

[1] Central LHIN Assessors followed standard interRAI assessment protocols, using all sources of information to complete the RAI-HC and interRAI-HC assessments. This typically included speaking with the individual, the person's family, if available, and persons directly involved in the individual's supports, as well as record review. However, there are certain items in the assessment that are only to be answered by the person in order to ensure that his/her thoughts, beliefs, or feelings are accurately reflected.

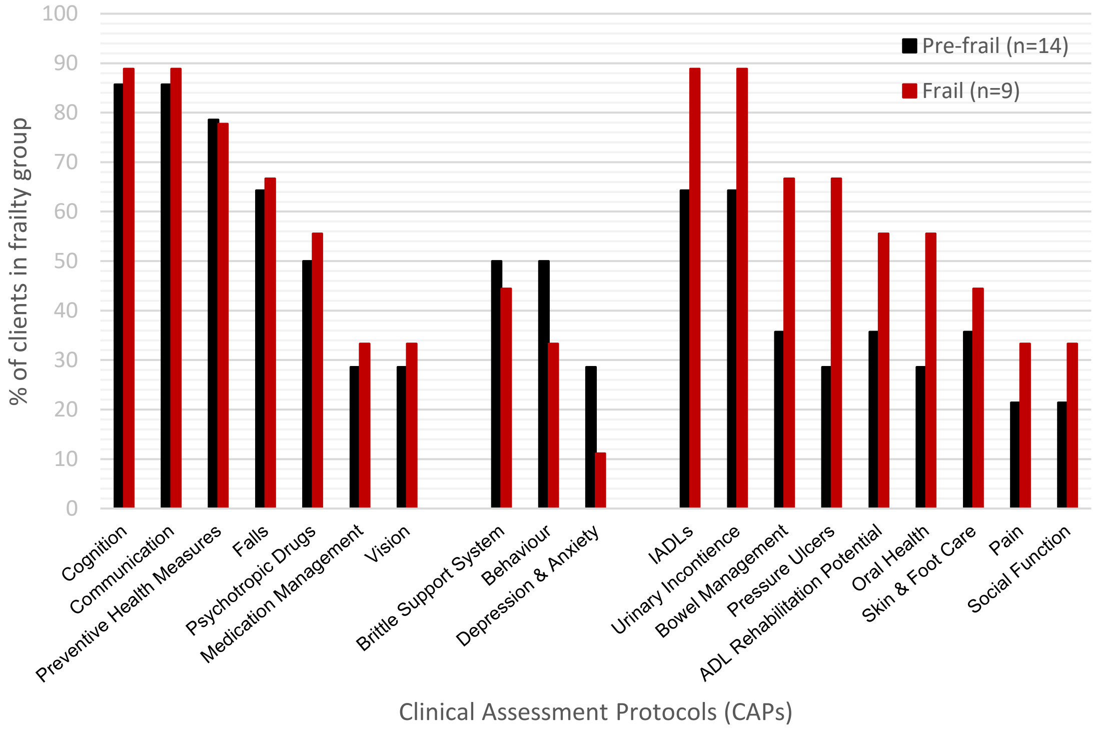
The findings

Needs and planning focus

Home care sector. The Baseline Report (Martin, Ouellette-Kuntz & Choi, 2018) showed that the elements most often contributing to frailty status, based on the Home Care-IDD Frailty Index, related to unsteady gait, stair climbing, short-term memory problem, fear of falling, social isolation, and overall change in care needs.

The home care assessment includes over 300 items that assess an individual's status in key life domains. These individual items are brought together to trigger "Clinical Assessment Protocols" (CAPs) that identify areas that warrant further attention – for example, further assessment or services. Figure 2 shows the frequency for CAPs triggered in the baseline home care assessment among those who were identified as pre-frail and frail. Note that results are shown only for those CAPs triggered by at least 5 individuals in order to both preserve anonymity and show a meaningful breakdown by frailty status.

Figure 2. Clinical Assessment Protocols (CAPs) Triggered at Baseline by Frailty Status



As shown in Figure 2, individuals who were frail triggered a higher number of CAPs overall, and had higher triggering of all CAPs with three exceptions (i.e., Brittle Support System, Behaviour, Depression and Anxiety).

- More than 85% of individuals triggered both CAPs related to the **cognitive domain** of frailty – i.e., Cognition and Communication.
- Between one quarter and half of individuals triggered the three CAPs related to the **psychological domain** of frailty (i.e., Behaviour, Depression and Anxiety, and Psychotropic Drugs). As noted above, more individuals identified as pre-frail triggered CAPs related to Behaviour and Depression and Anxiety.
- With respect to the **social domain** of frailty, more individuals who were pre-frail triggered the CAP related to Brittle Support Systems (referring to informal support systems), whereas more individuals identified as frail triggered the CAP related to Social Function.
- One CAP fell into the **service use domain** of frailty – i.e., Preventive Health Measures, and there were similar proportions of individuals who were pre-frail and frail who triggered this CAP.
- The remaining 11 CAPs fell in the **physiological domain** (i.e., ADL Rehabilitation Potential, IADLs, Medication Management, Vision, Urinary Incontinence, Bowel Management, Falls, Oral Health, Skin and Foot Care, Pressure Ulcers, and Pain). Each of these CAPs was more often triggered by individuals identified as frail.

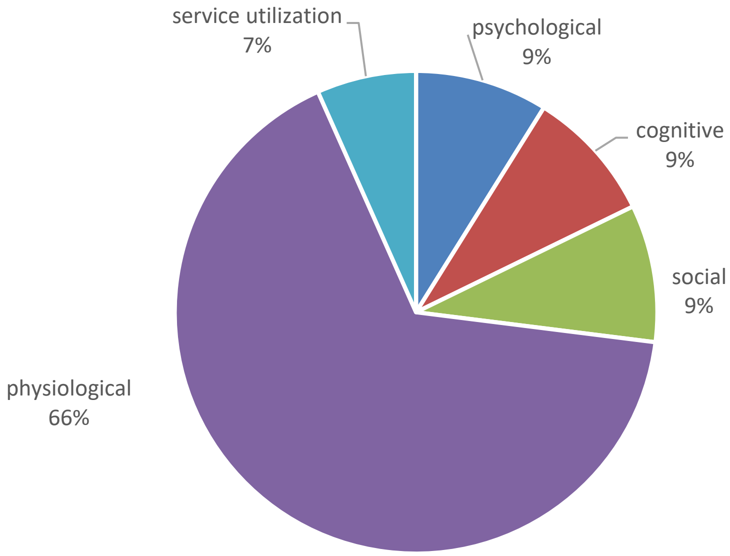
The available baseline care planning documentation from the home care sector was reviewed to identify actions to be taken based on the CAPs. This revealed that there were plans to address all CAPs in the **cognitive**, **psychological**, **service use**, and **physiological** domains.

Though the two CAPs in the **social domain** would be addressed for *some* who had triggered it, documentation showed that these CAPs were believed to have been falsely triggered about one third of the time (e.g., not an actual issue). It is unclear why assessors rated the CAPs as not being an issue, even though they had been triggered.

There did not appear to be differences in addressing CAPs by baseline frailty status.

Developmental Services (DS) sector. Using the care plan template, the DS sector staff identified a total of 315 deficits across the 23 clients who were frail or pre-frail at baseline. As shown in Figure 3, the majority of these fall under the **physiological domain** (66%).

Figure 3: Distribution of deficits identified by the DS sector at baseline across frailty domains



The eight most common physiological deficits, affecting at least 50% of clients, were:

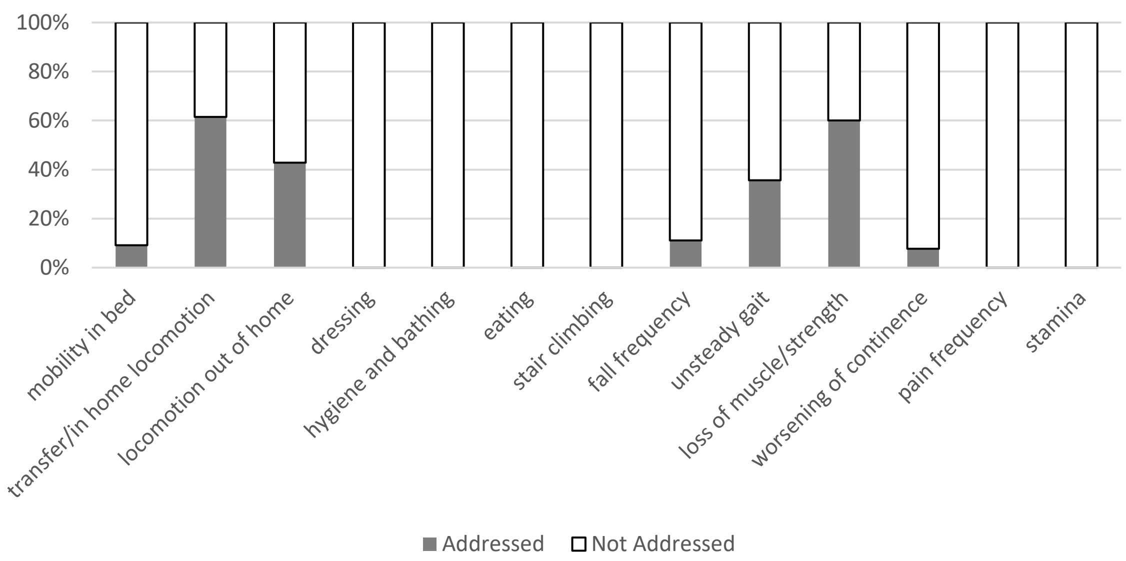
- ADL decline in hygiene and bathing (70%), in dressing (61%), in locomotion out of the home (61%), and in transfer/in-home locomotion (57%);
- unsteady gait (61%);
- stair climbing (57%);
- pain frequency (57%);
- worsening of continence (57%); and
- stamina (52%).

In the **social domain**, changes in social activities were noted in 70% of clients with social isolation and loneliness being identified in 30% and 26%, respectively. Common deficits identified from the **psychological domain** include fear of falling (57%) and changes in behaviours (48%). Deficits from the **service utilization domain** included changes in caregiver/family support (52%) and recent hospital/ER visits (39%). The most commonly identified deficit from the **cognitive domain** was communication decline (39%).

When deficits were identified, attention was more likely to be given to the **psychological domain** with 25% of deficits identified being addressed in the care plans - namely changes in behaviour and fear of falling. This was followed by the **social domain** with 24% of deficits identified being addressed (predominantly related to changes in social activities), and the **cognitive domain** with 21% of deficits identified being addressed - specifically communication decline. Despite the high occurrence of **physiological** deficits, this domain received proportionately less attention in the care plans with only 13% of deficits identified being addressed. The service utilization domain was similarly generally absent from care plans with only 3 deficits (14%) being addressed. In all, 51 of the 315 deficits identified by the DS sector were addressed in the care plans.

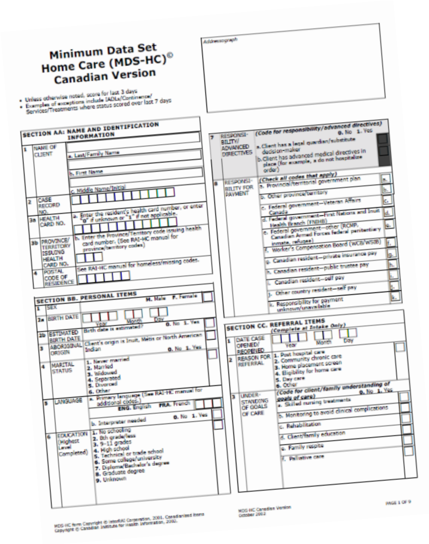
Common physiological deficits related to activities of daily living were not equally addressed. Deficits in mobility were more likely to be the focus of care planning compared to decline in dressing, hygiene and bathing or eating which were not addressed. Worsening of continence, pain, and stamina also tended to be ignored in the care plans.

Figure 4: Proportion of clients for whom a deficit was identified where the deficit was addressed vs. not addressed in the care plan



Eleven instances were noted where a deficit which had not been identified at baseline was addressed in the care plan. Seven of these were related to mobility deficits (i.e., ADL decline – Transfer/in home locomotion, locomotion out of home, unsteady gait, fear of falling) while the remainder concerned the social domain (i.e., social isolation, loneliness) and service utilization (i.e., change in caregiver/family support). This demonstrates the changing nature of frailty deficits and the ability of planners to adjust care plans to better meet the needs of individuals over time.

Similarities and differences across DS and home care sectors



Minimum Data Set Home Care (MDS-HC)© Canadian Version

- Unless otherwise noted, score for last 3 days
- Examples of exceptions include IADLs/Continence/ Services/Treatments where status scored over last 7 days

Addressograph

SECTION AA: NAME AND IDENTIFICATION INFORMATION

1 NAME OF CLIENT
a. Last/Family Name
b. First Name
c. Middle Name/Initial

2 CASE RECORD NO.

3a HEALTH CARD NO. a. Enter the resident's health card number, or enter "0" if unknown or "1" if not applicable.

3b PROVINCE/ TERRITORY ISSUING HEALTH CARD NO. b. Enter the Province/Territory code issuing health card number. (See RAI-HC manual for province/territory codes)

4 POSTAL CODE OF RESIDENCE See RAI-HC manual for homeless/missing codes.

SECTION BB. PERSONAL ITEMS

1 SEX **M.** Male **F.** Female

2a BIRTH DATE Year Month Day

2b ESTIMATED BIRTH DATE Birth date is estimated? **0.** No **1.** Yes

3 ABORIGINAL ORIGIN Client's origin is Inuit, Métis or North American Indian **0.** No **1.** Yes

4 MARITAL STATUS
1. Never married
2. Married
3. Widowed
4. Separated
5. Divorced
6. Other

5 LANGUAGE a. Primary language (See RAI-HC manual for additional codes.) **ENG.** English **FRA.** French
b. Interpreter needed **0.** No **1.** Yes

6 EDUCATION (Highest Level Completed)
1. No schooling
2. 8th grade/less
3. 9-11 grades
4. High school
5. Technical or trade school
6. Some college/university
7. Diploma/Bachelor's degree
8. Graduate degree
9. Unknown

7 RESPONSIBILITY/ ADVANCED DIRECTIVES *(Code for responsibility/advanced directives)* **0.** No **1.** Yes
a. Client has a legal guardian/substitute decision-maker
b. Client has advanced medical directives in place (for example, a do not hospitalize order)

8 RESPONSIBILITY FOR PAYMENT *(Check all codes that apply)*
a. Provincial/territorial government plan
b. Other province/territory
c. Federal government—Veteran Affairs Canada
d. Federal government—First Nations and Inuit Health Branch (FNIHB)
e. Federal government—other (RCMP, Canadian Armed Forces federal penitentiary inmate, refugee)
f. Worker's Compensation Board (WCB/WSIB)
g. Canadian resident—private insurance pay
h. Canadian resident—public trustee pay
i. Canadian resident—self pay
j. Other country resident—self pay
k. Responsibility for payment unknown/unavailable

SECTION CC. REFERRAL ITEMS *(Complete at Intake Only)*

1 DATE CASE OPENED/ REOPENED Year Month Day

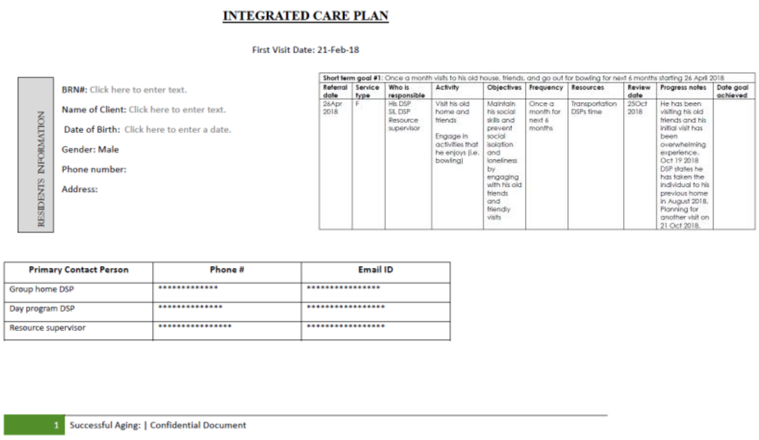
2 REASON FOR REFERRAL
1. Post hospital care
2. Community chronic care
3. Home placement screen
4. Eligibility for home care
5. Day care
6. Other

3 UNDERSTANDING OF GOALS OF CARE *(Code for client/family understanding of goals of care)* **0.** No **1.** Yes
a. Skilled nursing treatments
b. Monitoring to avoid clinical complications
c. Rehabilitation
d. Client/family education
e. Family respite
f. Palliative care

MDS-HC form Copyright © interRAI Corporation, 2001. Canadianized items Copyright © Canadian Institute for Health Information, 2002.

MDS-HC Canadian Version October 2002

PAGE 1 OF 9



INTEGRATED CARE PLAN

First Visit Date: 21-Feb-18

RESIDENTS INFORMATION

BRN#: Click here to enter text.
Name of Client: Click here to enter text.
Date of Birth: Click here to enter a date.
Gender: Male
Phone number:
Address:

Short term goal #1: Once a month visits to his old house, friends, and go out for bowling for next 6 months starting 26 April 2018

Referral date	Service type	Who is responsible	Activity	Objectives	Frequency	Resources	Review date	Progress notes	Date goal achieved
26Apr 2018	F	His DSP SIL DSP Resource supervisor	Visit his old home and friends Engage in activities that he enjoys (i.e. bowling)	Maintain his social skills and prevent social isolation and loneliness by engaging with his old friends and friendly visits	Once a month for next 6 months	Transportation DSPs time	25Oct 2018	He has been visiting his old friends and his initial visit has been overwhelming experience. Oct 19 2018 DSP states he has taken the individual to his previous home in August 2018. Planning for another visit on 21 Oct 2018.	

Primary Contact Person	Phone #	Email ID
Group home DSP	*************	****************
Day program DSP	**************	*****************
Resource supervisor	****************	*****************

1 Successful Aging: | Confidential Document

In both the home care and DS sectors, concerns related to **ADLs**, **incontinence**, and **falls** were identified and addressed.

Pain, while frequently noted by the DS sector (i.e., >50% of individuals), was not often identified as a concern in the home care assessment (i.e., 6 of 23 individuals triggered the Pain CAP). When the Pain CAP had been triggered, home care had documented plans to address the issue.

Both the DS and home care sectors paid attention to **social issues**, though this seemed to be less of a focus in home care. Often, issues related to social functioning and social supports were deemed to not be present by home care providers (in spite of triggering the related CAPs), who noted that no interventions were required. Given that this sector provides home-based health care services, it is not surprising that social issues received less attention. As DS supports and services aim to improve social inclusion, it is also not surprising that social issues were a focus in this sector (i.e., >50% of individuals).

Given the number of CAPs related to the physiological domain, the major focus of intervention in the home care sector was related to **physiological deficits**, which received the least attention in the DS sector. Again, this is not surprising given the focus of the home care and DS sectors.

Intersectoral nature of coordinated care planning

The care plans tend not to be explicit regarding intersectoral collaboration. There is evidence of involvement of occupational therapy, speech pathology, medicine, community recreational and fitness services, and volunteers along with DS staff in four of the 23 care plans.

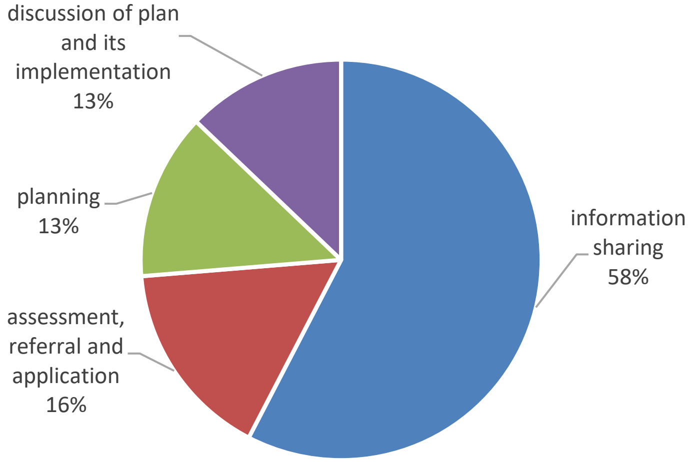
Through the communication logs however, the Care Coordinators reported having had on average a total of 67.6 contacts with diverse individuals per client over the 12-month project. Across the 23 clients, there were 150 contacts with the home care sector; an average of 6.5 per client. A variety of allied health professionals and community services were contacted less frequently; these included day programs, recreational services, mental health services, and the Developmental Service Ontario agency, as well as a music program coordinator, communication assistant, speech language therapist, dietician, behaviour therapist, occupational therapist, and social worker.

Care Coordinators initiated nearly 2/3 of contacts. Others who most often initiated contacts included direct support professionals, their supervisors, and the client's family. Less than 1% of contacts were initiated by the client or by an individual outside the DS sector. Most of the recorded contacts were from the Care Coordinators to direct support professional (24%), their supervisors (16%), the Project Coordinator (30%) hired specifically to manage this project, or Reena administrative staff (~17%). Approximately 9% of contacts were to family members and 2% with the client. Contacts with clients were from 15 minutes to 4.5 hours in duration (average: 51 minutes).

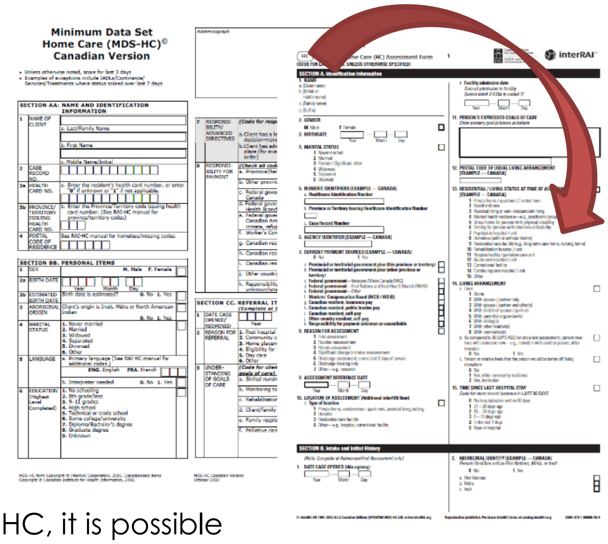
The majority of contacts were by email or online exchanges (68%) which took on average 15 minutes. Nearly 20% of contacts were by phone; these lasted on average 19 minutes. In-person contact was less common (13%) but these tended to be longer (average: 36 minutes). In all, care coordinators spent on average 19 hours per client in contact with various individuals over the course of the 12-month project in order to plan and implement the care plan (range: 2 hours for a pre-frail client whose care plan was completed in 4 months to 51.45 hours for a pre-frail client whose care plan extended over the entire year and resulted in a long-term care admission).

Contacts had different purposes. As shown in Figure 5, more than half of the contacts focused on information sharing.

Figure 5: Breakdown of contacts documented by care coordinators by focus



One year outcomes – Home Care sector



Minimum Data Set
Home Care (MDS-HC)©
Canadian Version

Change in instrumentation

In April 2018, home care transitioned from the RAI-HC to the interRAI HC assessment. This change resulted in the inability to calculate the Home Care-IDD Frailty Index (HC-IDD FI) score at follow-up, as several items are no longer available (i.e., delirium, communication decline, mood decline, behaviour worsening, locomotion outside, worsening incontinence, fear of falling, and pain disruption).

While it is no longer possible to obtain information on delirium, locomotion outside, fear of falling, and pain disruption in the interRAI HC, it is possible to use other variables in the assessment to understand the four remaining variables. Specifically:

- **Communication decline** was measured by using baseline and follow-up scores on two communication items (Expression and Comprehension) – if item scores were higher at follow-up, then the person has experienced a decline, whereas lower scores at follow-up indicate improvement.
- **Mood decline** was measured using baseline and follow-up scores on the Depression Rating Scale (DRS) – if DRS scores were higher at follow-up, then the person has experienced a decline, whereas lower scores indicate improvement.
- **Worsening in behaviour** was measured by examining the presence/absence of specific behaviours (i.e., wandering, verbal abuse, physical abuse, socially inappropriate or disruptive behaviour, and resisting care) at baseline and follow-up – presence at baseline but not at follow-up was considered improvement, whereas absence at baseline and presence at follow-up was considered indicative of decline.
- **Worsening in incontinence** was measured using baseline and follow-up on the bladder incontinence item – if the score was higher at follow-up then the person has had a decline, whereas a lower score at follow-up indicates improvement.

Further, in the HC-IDD FI, **changes in self-care skills** (i.e., bed mobility, locomotion, dressing upper and lower body, eating, toilet use, hygiene, and bathing) was calculated by combining each item with a general item on ADL decline. With the availability of longitudinal data in the current project, change was determined by comparing levels of independence for each item at baseline and follow-up. If scores were higher at follow-up, then the person has experienced a decline in independence, whereas lower scores at follow-up indicate improvement (i.e., less dependence). Information is also provided on whether the person has experienced a recent overall decline in ADLs at follow-up.

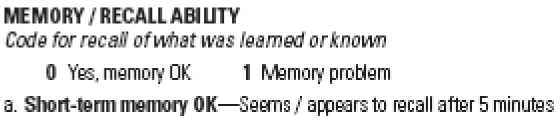
Evaluating and interpreting change based on home care assessments

In examining change over time, it is important to note that:

1) All individuals had the potential to remain stable
2) Only those individuals who did not have the lowest possible score on an item could improve in that area over time
3) Only those who did not have the highest possible score on an item could decline in that area over time.

Two examples to illustrate stability, improvement, and decline are provided below.

Example 1: Short-term memory


MEMORY / RECALL ABILITY
Code for recall of what was learned or known
0 Yes, memory OK 1 Memory problem
a. **Short-term memory OK**—Seems / appears to recall after 5 minutes

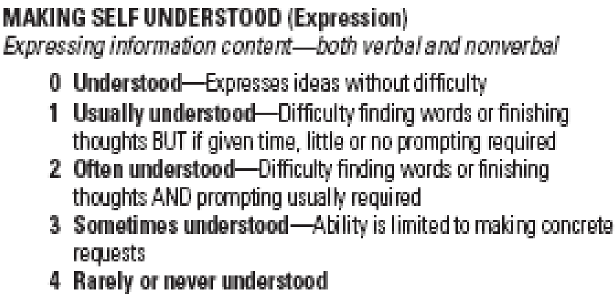
Coding	Follow-up assessment	
Baseline assessment	**0. Memory OK**	**1. Memory Problem**
0. Memory OK	Stable	Decline
1. Memory Problem	Improve	Stable

In order to show ***improvement*** in short-term memory over time, the individual must have a problem noted on the baseline assessment, but not at follow-up.

In order to show ***decline***, the individual must have no problem noted on the baseline assessment and a problem listed on the follow-up assessment.

A person who has no short-term memory problem at both baseline and follow-up has remained ***stable***; the same is true if a problem is noted on both assessments.

Example 2: Expressive communication


MAKING SELF UNDERSTOOD (Expression)
Expressing information content—both verbal and nonverbal
0 **Understood**—Expresses ideas without difficulty
1 **Usually understood**—Difficulty finding words or finishing thoughts BUT if given time, little or no prompting required
2 **Often understood**—Difficulty finding words or finishing thoughts AND prompting usually required
3 **Sometimes understood**—Ability is limited to making concrete requests
4 **Rarely or never understood**

In order to show ***improvement*** in expression over time, the individual must have a *lower* score at follow-up. Those with a baseline score of 0 cannot have a lower score.

In order to show ***decline***, the individual must have a *higher* score at follow-up. Those with a baseline score of 4 cannot have a higher score.

A person who has the same score on both assessments has remained ***stable***

Coding	Follow-up assessment				
Baseline assessment	**0. Understood**	**1. Usually understood**	**2. Often understood**	**3. Sometimes understood**	**4. Rarely/Never understood**
0. Understood	Stable	Decline	Decline	Decline	Decline
1. Usually understood	Improve	Stable	Decline	Decline	Decline
2. Often understood	Improve	Improve	Stable	Decline	Decline
3. Sometimes understood	Improve	Improve	Improve	Stable	Decline
4. Rarely/Never understood	Improve	Improve	Improve	Improve	Stable

Change observed between baseline and follow-up assessments

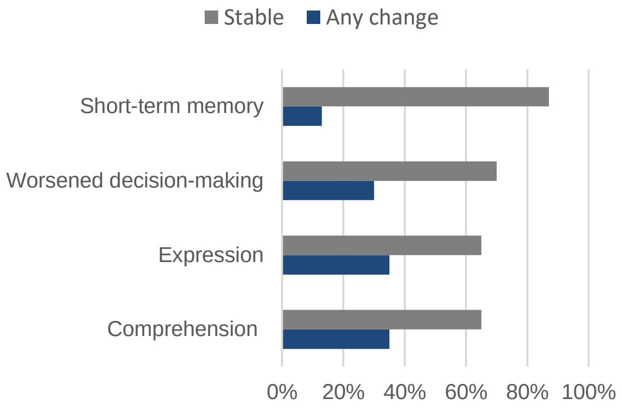
The figures bellows show the prevalence of **stability** vs **any change** (improvement or decline) in each domain over the study period. The direction of change is also described in the accompanying text (i.e., improvement or decline).

Cognitive domain

The most **stability** was experienced in the cognitive domain, overall.

Among those with capacity for **improvement**, 14% improved in short-term memory, 80% in decision-making, 14% in expression, and 17% in comprehension.

Decline was experienced among 17% for decision-making, 25% for expression, and 19% in comprehension. There was no decline observed in short-term memory.

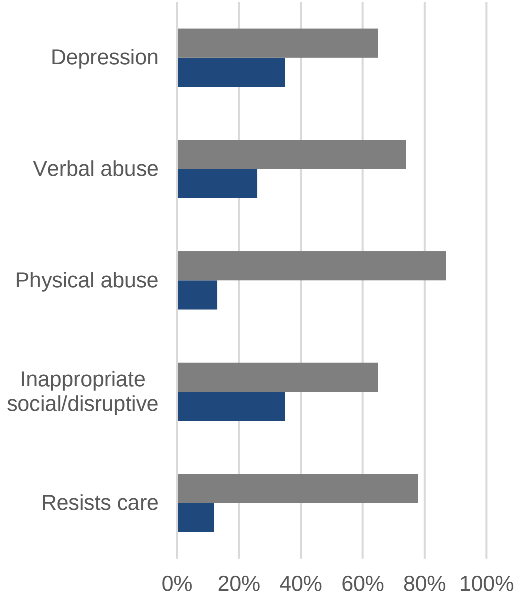


Psychological domain

While **stability** was noted for over 60% for all items, the most improvement was seen in this domain.

Among those with capacity for **improvement**, 100% improved in three of the four considered behaviours (i.e., verbal abuse, physical abuse, and socially inappropriate or disruptive behaviour). Just over half of individuals improved in terms of signs of depression (60%) and exactly half improved in terms of resisting care.

Decline was observed among fewer than 10% of individuals in depressive symptoms (9%), verbal abuse (6%), physical abuse (5%), and resisting care (7%). Approximately 17% worsened in terms of socially inappropriate or disruptive behaviour.

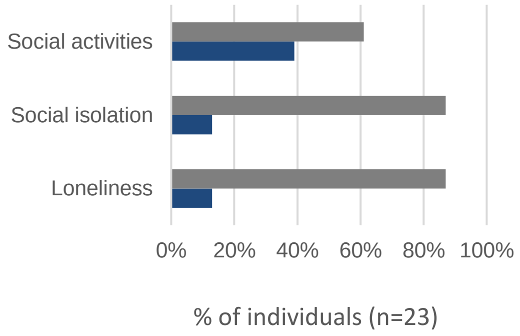


Social domain

Again, while **stability** was most likely across items in the social domain, some improvement was noted.

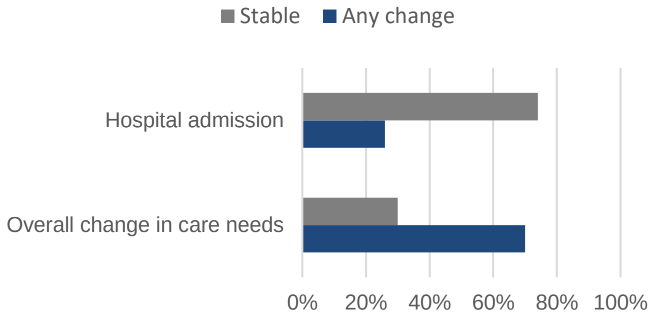
Among those with capacity for **improvement**, 100% experienced reduced feelings of loneliness, over three quarters no longer had reduced social activities, and about one quarter improved in terms of social isolation.

In terms of **decline**, 14% experienced a decline in social activities and loneliness was newly noted in 5% of individuals. No worsening was observed in social isolation.



Service use domain
Among those who had experienced an overall change in care needs at baseline, this was no longer true for 81% at follow-up. This means that they had not experienced further negative changes.

Reduction in the number of hospital admissions was seen for half of individuals, while an increase was observed for 9%.

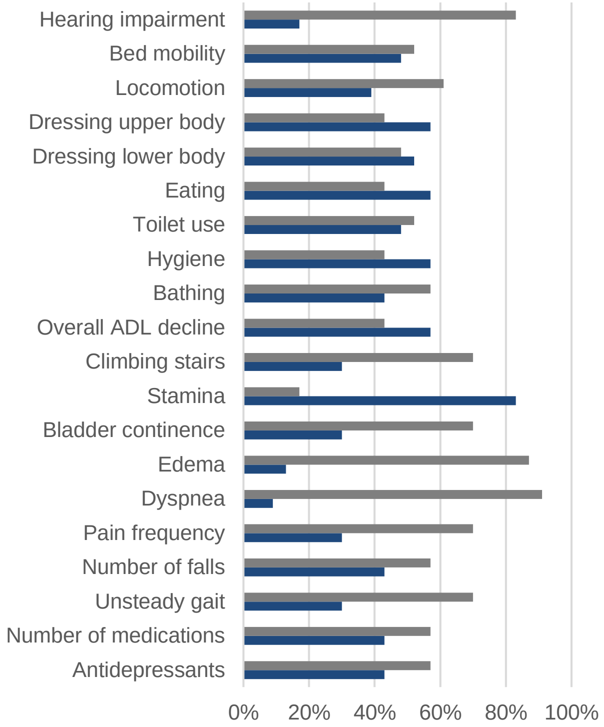


Physiological domain
Individuals experienced the greatest **change** in the physiological domain.

More **improvement** than decline was noted for locomotion (38% vs. 21%), climbing stairs (30% vs. 14%), edema (40% vs. 4%), dyspnea (67% vs. 0%), pain frequency (57% vs. 14%), number of falls (75% vs. 18%), unsteady gait (41% vs. 0%), and use of antidepressant medication (63% vs. 33%).

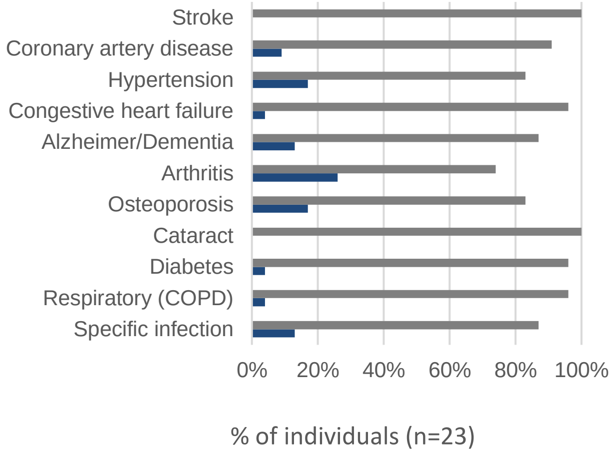
However, more **decline** than improvement was noted with respect to independence in toilet use (39% vs. 27%) and overall number of medications taken (43% vs. 17%).

There were similar proportions of improvement and decline for bed mobility (36% improve vs. 33% decline), bathing (26% improve and 27% decline), and bladder continence (22% improve vs. 19% decline).



With respect to disease diagnoses, **improvement** is understood as either resolved (i.e. no longer present) or managed (i.e., no longer needing intervention or monitoring). Such improvement was observed in all individuals with coronary artery disease, congestive heart failure, diabetes, and COPD. Improvement was also noted for 57% of those with hypertension, 60% with arthritis, and 50% with osteoporosis.

Decline is understood as either a new diagnosis (i.e., wasn't present before) or requiring management (i.e., now actively monitoring or treating). This was noted in 13% of individuals for infections, 10% for Alzheimer/Dementia and arthritis, and 9% for osteoporosis.



One year outcomes – DS sector

Of the 23 individuals who were frail or pre-frail at baseline, care plans indicated outcomes for 18 of them. Despite 51 deficits being addressed across the 23 care plans, stability or change was only reported for 15 deficits addressed.

Stability in terms of maintenance of muscle/strength was reported for one individual.

Decline was reported for three individuals in areas ranging from mobility (1), diabetes (1), behaviour (1) and osteoporosis (1).

Improvement was noted for nine individuals in areas ranging from mobility/gait (4 individuals – 5 deficits), muscle/strength (1), social activities (3), and social isolation (1).

The care plans also referred to other types of outcomes, such as:

- Client referred/waiting for an assessment (3),
- Client assessed (4),
- Client waiting for services and supports (6),
- Client moved or in process of moving to a long-term care facility (2), and
- Staff training occurred or scheduled (2).

According to the care plans submitted, after a year, assessments/referral are still pending for deficits such as transfer/in-home locomotion (2), and changes in caregiver/family support (1).

Assessments have been completed without further change to the care plan related to unsteady gait (1) and short-term memory loss (1).

In addition, some individuals are still waiting for services and supports related to short-term memory loss (2), changes in behaviour (2), Dementia/Alzheimer's (1), communication decline (1), and loneliness (1).

Lessons Learned and Recommended Next Steps

In this project, information on frailty (based on home care assessments) was shared with the DS sector to determine how this knowledge affected care planning and outcomes.

Lesson 1: Assessing, documenting & using information about frailty improves outcomes.
Coordinators in the DS sector developed a care plan template that allowed documentation of frailty-related areas of concern and associated actions and outcomes. However, this was not consistently completed for all individuals. Further, documentation in the care plan was not standardized in that it is unclear whether absence of information indicates absence of action or outcome.

Care planning in the home care sector is done using the interRAI HC assessment instrument; it is completed as part of regular practice and on a regular basis. Information is gathered using all sources of information, including speaking with the individual, family (if available), and others directly involved in the individual's supports, as well as review of available records. All items in the assessment are coded in a standardized way, and all items must be answered.

While some level of decline occurred in all domains, the findings suggest that when issues related to frailty are identified, this knowledge leads to actions that have the potential to improve client outcomes.

In looking at issues and related actions, the DS care plans showed that particular attention was paid to mobility – including falls, gait, locomotion, and strength. However, these care plans did not always note related outcomes. In looking at follow-up home care assessments, we see that there were fewer individuals who had experienced further overall decline in ADLs and care needs, and many had improved in terms of number of falls, unsteady gait, and climbing stairs. Similarly, the DS care plan shows they paid attention to social issues, but outcomes were not consistently noted. The follow-up home care assessment shows that all individuals who previously displayed problematic behaviours (such as verbal or physical abuse) no longer exhibited them, and that mood, feelings of loneliness, and participation in social activities all improved. It is important that issues, actions, and outcomes are all consistently noted in a standardized manner so that these may be evaluated and tracked over time.

Lesson 2: Involving multiple people & sectors increases the complexity of planning.
There are several DS providers who support adults with IDD in group homes on a daily basis. As aging-related issues fall outside of their expertise, strong partnerships with the health care sector are important to address the needs of adults with IDD who are frail.

From the documentation reviewed, it appears that some issues were being addressed by both the home care and DS sectors, but it is unclear whether each sector was aware of the actions of the other. Further, the extent to which health providers were part of DS care planning decisions was unclear from the documentation. When involved in supporting individuals with IDD identified as frail, providers from other sectors need to be seen as being part of the team, alongside DS providers. Health providers should be involved in decision-making about supports and services, as well as monitoring actions and outcomes.

Three inter-related recommendations stemming from this project are offered to further assist the home care and DS sectors support adults with IDD who are frail:

Recommendation 1: Training to build capacity in the DS sector related to frailty

Many of the aging-related issues experienced by individuals with IDD fall outside of the expertise of DS providers. However, they have an important role to play in noting and addressing issues related to frailty.

In order to ensure that all team members are able to meaningfully participate in planning efforts, it would be beneficial for everyone to have knowledge and solid understanding not only of frailty and its consequences, but also of how to recognize and document related signs.

Recommendation 2: Development of a formal data sharing agreement

The role of the home care sector is to assess and identify health-related issues in Ontarians referred for their services. Given that the frailty deficits stem from the home care assessment, there is a need to develop agreements between the home care and DS sectors to share assessment information, rather than having the DS sector try to replicate that information on its own (as seen in the care plan template). *In fact, access to the home care assessments/database happened toward the end of the project*. It will be important to formalize this arrangement going forward, and consider how home care might be able to access DS documentation as well.

Consideration of using a common care planning template is also warranted – i.e., an "integrated care plan", which would be shared and updated by both sectors.

Recommendation 3: Development of intersectoral collaboration protocols

As previously noted, while there was evidence of interaction between the DS and home care sectors (as per the communication logs), the extent to which decisions and plans were made collaboratively could not be assessed. Development of a team planning protocol that clearly defines the roles and responsibilities for the home care and DS sectors for supporting clients at Reena identified as frail would help to reduce duplication of efforts, as well as ensure that there are no gaps in supports. For example, if the home care assessment is used as the basis for planning, discussion could focus on triggered Clinical Assessment Protocols (CAPs) and sectors' roles in addressing them.

It would also be important to establish a referral protocol between Reena, Mary Centre, and the Central Local Health Integration Network. The home care assessment protocol provides the information for identifying and monitoring signs of frailty. As per the Consensus Statement (Ouellette-Kuntz et al., 2018), adults with IDD 40 years of age and older should be assessed and monitored for signs of age-related decline and frailty. In the absence of a valid stand-alone measure of frailty, these individuals should be referred to home care and CAPs triggered from the home care assessment should be used to inform the development of an integrated care plan. Regular repeat home care assessment results should be shared with DS staff in order to update the integrated care plan and monitor impacts of supports

Given the importance of intersectoral collaboration in the context of supporting adults with IDD who are frail, information on key elements (based on the authors' ongoing work) is provided below.

Intersectoral collaboration in the context of supporting adults with IDD who are frail

As part of a study funded by the Canadian Frailty Network and Reena, a case study approach was used to explore collaboration between the DS and home care sectors in the context of supporting three adults with IDD identified as pre-frail or frail.

A total of 25 individuals were interviewed, including adults with IDD, family members, and providers in each sector. The open-ended interview questions targeted conditions for effective intersectoral collaboration identified in the scientific literature. In particular we asked about: necessity (e.g., when the need for collaboration was identified), opportunity (e.g., how the collaboration was supported), capacity (e.g., were the needed skills and resources available), relationships (e.g., how well did everyone work together), planned action (e.g., what actions were taken by whom), and sustained outcomes (e.g., monitoring of outcomes).

The finding suggest that these six major themes (i.e., necessity, opportunity, capacity, relationships, planned action and sustained outcomes) manifested in all groups with one exception: individuals with IDD and family members did not speak of sustained outcomes. As such, though no published studies have reported on conditions that support intersectoral collaboration involving the DS sector specifically, this study supports the notion that the six domains are also relevant to intersectoral action to support adults with IDD who are frail.

Given that planning in the DS sector is very much focused on individuals rather than initiatives, further examination of the link between these six domains and person-centred approaches to planning is needed. This would help to see the link between the two approaches to planning (i.e., person-centered and intersectoral) and their relevance and importance in the context of supporting individuals who are frail. Work with individuals with IDD and families on the best way to share information about intersectoral collaboration is needed in general – and on capacity, action, and plans to sustain outcomes in particular.

In order to increase awareness and knowledge of intersectoral collaboration, an infographic was developed to disseminate research findings in a practical way to support action by those involved in intersectoral collaboration (see figure 6, below). Some further resources are also suggested to support and encourage effective intersectoral collaboration (see page 21).

Intersectoral Collaboration

Because frailty is complex.

01

Know what you need

Know **who** needs to be involved
Know **why** you are working together
Know **what** drives the work you are doing

02

Find the opportunities

Get support from your **organization**
Engage **important & strategic** stakeholders
Identify and support your **champions**

03

Build capacity

Develop informal & formal **arrangements**
Identify **knowledge, skills, & resources**
Link **within & across** organizations
Share leadership, power, & rewards

04

Develop relationships

Build **alliances** early on
Develop **trust and respect**
Communicate effectively and often

05

Plan & act on those plans

Take on **your** role & be accountable
Know and support the role of **others**
Do the **doable**
Check in regularly on actions & results

06

Don't stop – keep it going

Develop **processes & tools** to sustain action
Celebrate results and successes!

A person who is becoming frail needs supports from health and social sectors. **Intersectoral collaboration** is key to meeting the person's current, emerging, and future needs.

Lakehead UNIVERSITY
Canadian Frailty Network
MAPS
Reena *Reena Ready* to live, work and play in the community.
Queen's UNIVERSITY

For more information: www.mapsresearch.ca

Figure 6. Intersectoral collaboration in the context of supporting individuals with IDD who are frail.

References

Barabash, T., Deck, E., Ouellette-Kuntz, H., & Martin, L. (2019). How to best support adults with intellectual and developmental disabilities (IDD) who are frail: an international consensus statement. Kingston, ON: Multidimensional Assessment of Providers and Systems.

Martin, L., McKenzie, K., & Ouellette-Kuntz. (2018). Once frail, always frail? Frailty transitions in home care users with intellectual and developmental disabilities. *Geriatrics and Gerontology International, 18*(4), 547-553.

Martin, L., Ouellette-Kuntz, H., & Choi, A. (2018). A baseline profile of clients assessed with the RAI-HC. Kingston, ON: Multidimensional Assessment of Providers and Systems.

McKenzie, K., Ouellette-Kuntz, H., & Martin, L. (2015). Using an accumulation of deficits approach to measure frailty in a population of Ontario home care users with intellectual and developmental disabilities: an analytical descriptive study. *BMC Geriatrics, 15:* 170.

Ontario Partnership on Aging and Developmental Disabilities. (2005). *Aging with a Developmental Disability – Transition Guide for Caregivers*. Thornhill, ON: Authors.

Ouellette-Kuntz, H., Martin, L., Burke, E., McCallion, P., McCarron, M., McGlinchey, E., Sandberg, M., Schoufour, J., Shooshtari, S., & Temple, B. (2019). How best to support individuals with IDD as they become frail: development of a consensus statement. *Journal of Applied Research in Intellectual Disabilities, 32*, 35-42.

Resources

Partnership Self-Assessment Tool

The Partnership Self-Assessment Tool is a questionnaire that various partners can complete to examine the strengths and weakness of the partnership. Answers can help guide organizations and individuals to make the partnership increasingly successful. The tool measures a key indicator of a successful collaborative process: synergy (partnership synergy).

> https://atrium.lib.uoguelph.ca/xmlui/bitstream/handle/10214/3129/Partnership_Self-Assessment_Tool-Questionnaire_complete.pdf?sequence=1&isAllowed=y

The Partnership Handbook

This tool provides practical tips, checklists, stories and strategies to help develop, sustain and evaluate a partnership. For instance, the guide includes checklists and questions to assess individual and organizational skills for partnering, partnership readiness and steps for closing a partnership.

> http://publications.gc.ca/site/eng/245551/publication.html

Self-Evaluation Tool for Action in Partnerships

This tool allows members of partnerships to evaluate themselves and learn about the requirements for effective partnership work.

> https://en.healthnexus.ca/sites/en.healthnexus.ca/files/resources/selfevaluationtool.pdf

Author Information

Hélène Ouellette-Kuntz
Professor
Queen's University
Tel (613) 548-4417 x. 1198
Fax (613) 548-8135
helene.kuntz@queensu.ca

Lynn Martin
Professor
Lakehead University
Tel (807) 766-7245
Fax (807) 766-7225
lynn.martin@lakeheadu.ca

Tori Barabash
Queen's University

Eve Deck
Lakehead University