

Data Brief

Interactive presentations
to disseminate key
elements of intersectoral
collaboration to support
adults with IDD who are
frail in the community

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MAPS
MULTIDIMENSIONAL ASSESSMENT
OF PROVIDERS AND SYSTEMS

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Introduction

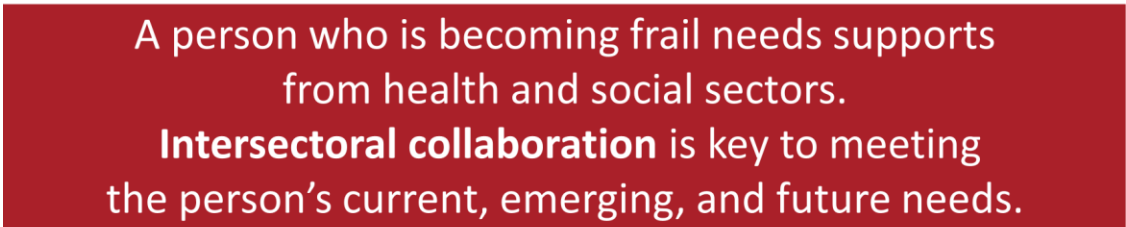
Frailty is understood as the presence of multiple deficits across multiple domains, and is widely used to study health and aging. Adults with intellectual and developmental disabilities (IDD) experience higher rates of frailty at earlier ages than the general population, though very few research teams have studied frailty in the context of IDD.

To raise awareness and guide action, an international consensus statement on how to support adults with IDD as they become frail was developed; it relied on several different consensus-building methods and intensive discussions of actions to take based on fictional cases (Ouellette-Kuntz et al., 2019). The consensus statement identified two core principles (person-centred approach; aging in place) that underlie seven inter-related actions to support adults with IDD who are frail: (1) consider frailty at an earlier age than in the general population; (2) focus on improvement and maintenance as goals; (3) coordinate assessments and services through intersectoral collaboration; (4) prioritize safety; (5) plan for the future; (6) consider the needs of informal and formal caregivers; and (7) grow the evidence base. A recent study of care plans for 23 adults with IDD identified as frail supports the face validity and real-world applicability of the consensus statement to supporting adults with IDD who are frail.

In the context of adults with IDD who are frail in the community, supports and services are often provided by both home care (HC) and developmental services (DS) sectors. As such, **intersectoral collaboration** is needed to plan and coordinate supports and services, to support advocacy, and to monitor outcomes. While intersectoral collaboration has been studied in the context of health care, no research appears to have been conducted in the field of IDD. Our team used a case study design to understand collaboration between a DS and an HC organization to support three adults with IDD who had been identified as frail (Martin, Deck, Barabash, & Ouellette-Kuntz, in press). We conducted 25 interviews asking a series of open-ended questions that targeted known conditions for effective intersectoral collaboration: i.e., necessity (e.g., when did they understand the need to collaborate?), opportunity (e.g., how were they supported to collaborate?), capacity (e.g., did they have the necessary skills and resources to collaborate?), relationships (e.g., how do they describe the quality of their relationship with collaborators?), planned action (e.g., what are the roles and responsibilities of each sector in organizing and delivering supports?), and sustained outcomes (e.g., how are outcomes monitored within and across sectors?). Qualitative analysis of the interviews revealed that each of the six conditions was important to the different participant groups, thus providing evidence of the theoretical and practical relevance of these six conditions in this context.

Infographics, videos, and workbooks highlighting information about the frailty consensus statement and key conditions for effective intersectoral collaboration were created to promote awareness and support action (see Figures 1 and 2 for examples). ***This Data Brief focuses on the learnings from an interactive webinar (November 19, 2019) and a conference presentation (December 9, 2019) in which these resources were shared with DS and HC professionals.***

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Value of the data

These data provide useful information to front-line providers, administrators, and decision-makers. We learned that:

- The knowledge of frailty in the context of IDD among developmental services and health care professionals is inadequate.
- Among the frailty consensus statement actions, intersectoral collaboration is recognized as one of the most important to providers. Relationships emerged as most important element of effective intersectoral collaboration.
- Webinar participants most often mentioned the need for help with intersectoral collaboration, whereas support with early consideration of frailty was most common among conference participants. In the context of intersectoral collaboration, webinar participants most often noted the need for help with elements related to Sustained Outcomes, Capacity, and Relationships.
- The data revealed that webinar participants felt that they were equally likely to use any of the different resources listed, though workbooks/guides and videos emerged as the most popular resources for webinar and conference participants, respectively. The majority of both groups of participants noted that they would use resources for all stated purposes (i.e., in own practice, share with others, use in advocacy).

As such, these data may be used to plan and implement training on frailty in the context of adults with IDD, as well as to support efforts to build and maintain strong intersectoral collaborations.

Data

Participants

A total of 80 individuals logged in to the webinar. At the start of the session, participants indicated whether they were alone or with others (i.e., 2, 3, 4, or 5+ others); based on their responses, it is estimated that a minimum of 114 people attended the webinar. A further 25 individuals participated in a similar but separate event held in French during a larger conference on frailty in Ottawa, ON. Table 1 provides information related to the 80 individuals who logged in to the webinar. In instance where there were multiple people at the same computer, the province and sector are applicable to all participants, though the primary role and current knowledge of topic may not.

Characteristics of Webinar Participants

Characteristics	Responses	Participants (n=80) % (n)
Province	Alberta Manitoba Nova Scotia Ontario Unknown/Did not respond	1.3% (1) 1.3% (1) 1.3% (1) 87.5% (70) 8.8% (7)
Sector	Developmental services – government Developmental services – provision Developmental services – other Health – government/LHIN Health – home care Health – long-term care Health – other Research/Academia Other Unknown/Did not respond	3.8% (3) 30% (24) 18.8% (15) 12.5% (10) 3.8% (3) 6.3% (5) 16.3% (13) 2.5% (2) 6.3% (5) (0)
Primary role	Person with IDD Family member of a person with IDD Direct service provider Manager/Supervisor Planner Policy analyst Student Other	1.3% (1) 1.3% (1) 33.8% (27) 31.3% (25) 8.8% (7) 2.5% (2) 1.3% (1) 20.0% (16)
Current knowledge of topic	I know nothing I know a little I know some I know a lot	5.0% (4) 36.3% (29) 46.3% (37) 12.5% (10)

Responses to poll questions

Poll questions were presented on the slides, and participants were asked to answer the question. In the case where there were multiple participants at the same computer, they were asked to answer the poll question based on consensus; if there was no consensus (i.e., persons in the group disagreed about the response), the comment box was used to include other responses. As such, responses are provided for the estimated number of 114 participants.

Knowledge of frailty in the context of IDD (n=114; Webinar participants only)

Poll questions	Responses	% (n)
Frailty occurs among persons with IDD as it does in those without	True False* Missing	49.1% (56) 31.6% (36) 19.3% (22)
Among persons with IDD, those with Down syndrome are more likely to be frail	True* False Missing	48.2% (55) 31.6% (36) 20.2% (23)
Among adults with IDD, frailty increases one's risk of dying	True* False Missing	62.3% (71) 7.0% (8) 30.7% (35)
Among adults with IDD, frailty is irreversible	True False* Missing	19.3% (22) 50.0% (57) 30.7% (35)
Have you heard about or used the consensus statement before?	Yes, heard about it/used it in work No, have not heard about/used it Missing	7.9% (9) 78.1% (89) 14.0% (16)

*Denotes correct response

Most important actions and conditions (n=114; Webinar participants only)

Poll questions	Responses	% (n)
Which [consensus statement] recommendation do you consider the most important? ¹	Frailty must be considered earlier Improvement & maintenance are viable goals Safety is a priority Intersectoral collaboration is needed Informal and formal caregivers have needs Planning for the future is important The evidence base must be grown	19.4% (7) 5.6% (2) 11.1% (4) 38.9% (14) 2.8% (1) 19.4% (7) 2.8% (1)
Which of the [key conditions] is the most important for effective intersectoral collaboration? ^{2,3}	Necessity Opportunity Capacity Relationships Planned action Sustained outcomes	4.8% (4) 11.9% (10) 13.1% (11) 35.7% (30) 21.4% (18) 13.1% (11)

¹n=78 missing (68.4%) among webinar participants; percentages reported are based on n=36

²n=30 missing (26.3%) among webinar participants; percentages reported are based on n=84

Actions and conditions participants need the most support with

Poll questions	Responses	Webinar (n=114)	Conference (n=25)
		% (n)	% (n)
Which [consensus statement] recommendation do you most need help with to implement it in practice? ¹	Frailty must be considered earlier	16.1% (15)	47.8% (11)
	Improvement & maintenance are viable goals	10.8% (10)	4.4% (1)
	Safety is a priority	0	17.4% (4)
	Intersectoral collaboration is needed	37.6% (35)	8.7% (2)
	Informal and formal caregivers have needs	9.7% (9)	0
	Planning for the future is important	19.4% (18)	17.4% (4)
	The evidence base must be grown	6.5% (6)	4.4% (1)
For which [key conditions] do you most need help with to implement it in practice? ²	Necessity	4.6% (3)	
	Opportunity	9.2% (6)	
	Capacity	23.1% (15)	
	Relationships	20.0% (13)	
	Planned action	13.8% (9)	
	Sustained outcomes	29.2% (19)	

¹n=21 missing (18.4%) among webinar participants and n=2 missing (8.0%) among conference participants; percentages reported are based on n=93 and n=23, respectively.

²n=49 missing (43.0%) among webinar participants; percentages reported are based on n=65. This information was not collected as part of the conference.

Use of resources

Poll questions	Responses	Webinar (n=114)	Conference (n=25)
		% (n)	% (n)
What type of resources are you most likely to use? ¹	Checklists	3.0% (2)	0
	Comprehensive reports	0	0
	Infographics	4.5% (3)	0
	Online courses	3.0% (2)	8.0% (2)
	Questionnaires/Self-assessments	4.5% (3)	12.0% (3)
	Research articles	4.5% (3)	12.0% (3)
	Videos	11.9% (8)	36.0% (9)
	Workbooks/Guides	20.9% (14)	4.0% (1)
	Equally likely to use all listed above	47.8% (32)	28.0% (7)
How do you anticipate using these resources? ²	Use in my own practice	9.4% (8)	12.5% (3)
	Share them with others	16.5% (14)	16.7% (4)
	Use them in advocacy	4.7% (4)	16.7% (4)
	Use them as described in all of the above	67.1% (57)	54.2% (13)
	I can't think of how I would use them	2.4% (2)	0

¹n=47 missing (41.2%) among webinar participants; percentages reported are based on n=67. There was no missing data for conference participants.

²n=29 missing (25.4%) among webinar participants and n=1 missing (4.0%) among conference participants; percentages reported are based on n=85 and n=24, respectively.

Design and methods

This Data Brief largely reports on the results of an interactive webinar where the research team presented findings and resources related to frailty and intersectoral collaboration in the context of IDD. Some of the content was also presented to participants at a health in IDD conference. The latter, while addressing aging and frailty, did not focus on intersectoral collaboration specifically. Ethical approval was granted by the Research Ethics Board at Lakehead University.

Recruitment

Approximately 1 month prior to the interactive webinar, persons affiliated with the Seniors Health Knowledge Network (see www.seniorshhealthknowledgenetwork.com; over 5000 members across multiple sectors) were invited to participate in the webinar via an email sent by the Network; a flyer describing the webinar was attached, and a link to the registration site was embedded in the email (and included on the flyer). Other persons known to the authors (e.g., other researchers, government representatives, advisory members) were also sent an email invitation to the webinar. The registration information noted plans to anonymize information collected during the webinar for inclusion in our research, and that individuals were free to attend without providing any information/input. A total of 157 people registered.

Conference participants were those who chose to attend the session; they were informed about plans to anonymize information collected during the session for inclusion in our research. Their responses were collected on cards distributed at the start of the session.

Participants

A total of 80 people logged in to the interactive webinar. At the start of the session, participants indicated (via a poll question function) whether they were alone at their computer or viewing the webinar with others (i.e., 2, 3, 4, or 5+ others). Based on their responses, it is estimated that a minimum of 114 people attended the interactive webinar. Twenty-five people attended the conference session.

Procedures

The webinar lasted one hour. At the start of the session, participants were reminded that the session was being recorded and archived for distribution through the research website, and that all questions and feedback would be used for reporting purposes. The session was divided into four parts: knowledge about frailty in the context of IDD, the frailty consensus statement, intersectoral collaboration in the context of supporting adults with IDD who are frail, and resources. Within each part, the researcher asked poll questions relevant to the topic, and then presented. All questions are provided within this Data Brief.

Analysis

Descriptive statistics were used to present the distribution of responses to poll questions. Missing data is reported for all questions. Given the extent of missing data, further analyses were not conducted (e.g., by sector, by primary role, etc.).

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