

From premise to practice: Applicability of a consensus statement for supporting adults with IDD who are frail

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Abstract

Background: Study of frailty in adults with intellectual and developmental disabilities (IDD) is relatively new. To build the body of literature, an international consensus statement on how to support adults with IDD as they become frail was developed based on fictional cases. This study examined the face validity and applicability of the consensus statement to real-world care planning.

Method: Twenty-three care plans for adults with IDD who were classified along the frailty continuum were reviewed. Documented goals, actions and outcomes were coded according to the consensus statement's principles and recommendations.

Results: The recommendations 'Improvement and maintenance are viable goals' and 'Intersectoral collaboration is needed' were documented the most often. Attention to the needs of formal and informal caregivers was mentioned the least often in care plans.

Conclusions: This study provides some support for the face validity of the consensus statement and its applicability to supporting adults with IDD who are frail.

KEYWORDS

applicability, care planning, consensus statement, frailty, IDD

1 | INTRODUCTION

Frailty has become a way of understanding age-related health decline and resource needs in the general population (Bronskill et al., 2010). Defined by the acquisition of age-related health deficits across multiple domains (e.g. biological, psychological, social and cognitive), frailty occurs in adults with intellectual and developmental disabilities (IDD) at earlier ages than the general population (Ouellette-Kuntz et al., 2015). As more adults with IDD are living longer (Coppus, 2013; Ouellette-Kuntz, Martin, & McKenzie, 2016), the need to assess and address frailty becomes increasingly important. However, the study of frailty in this population remains relatively new; there is no rich body of evidence to inform best practices. Given this lack of evidence, an international consensus statement was recently released that guides action to support adults with IDD as they become frail (Ouellette-Kuntz et al., 2019). The statement increases awareness about frailty among service providers and

support workers and guides their actions to address frailty-related needs, while also calling for future research to inform practice.

The consensus statement was developed by an international panel including researchers, service providers, policymakers and family members across over 20 countries who relied on several different consensus-building methods, including discussion of care needs of fictional cases with deficits shown to contribute to frailty in adults with IDD. These efforts led to the identification of two core principles that underlie action to support adults with IDD who are frail. The first emphasizes the need for a person-centred approach to planning, focused on the individual's strengths, abilities, and goals and promotes opportunities for meaningful choice-making. The second highlights the importance of ageing in place, while recognizing the rights of the individual as well as the concerns of family and other caregivers providing supports in the home. With these foundational principles in mind, seven interconnected actions are recommended: (1) considering frailty at an earlier age than in the

general population; (2) focusing on both improvement and maintenance as goals of support; (3) coordinating comprehensive and multidisciplinary assessments and supports through intersectoral collaboration; (4) prioritizing safety; (5) recognizing the importance of planning for the future (including advance care planning); (6) understanding the needs of informal and formal caregivers supporting the individual; and (7) growing the evidence base (Ouellette-Kuntz et al., 2019). While these were developed using a rigorous scientific approach, they have not yet been evaluated in practice.

Applicability, usability and relevance of evidence (such as consensus statements) are important considerations in its uptake into actual practice. While there is no defined method to assess applicability, proposed measures centre around the feasibility of a potential resource in a local space or context, considering social norms and available assets, and whether it will be worth the investment (Lavis et al., 2004; Wang et al., 2006). Using the international consensus statement on actions to support adults with IDD as they become frail as an example—if its two core principles were not valued in a particular setting or jurisdiction, the statement would likely be deemed unfeasible and irrelevant, and its recommendations would not be implemented.

Due to the lack of evidence related to frailty among adults with IDD in general, and the growing need to address the ageing-related needs in particular, there is value in examining the applicability of the consensus statement principles and recommendations to 'real world' practice. This would not only grow the evidence base, but also allow for identification of barriers and facilitators to their implementation. This paper demonstrates the extent to which the consensus statement principles and guidelines are present in care plans developed for older adults with IDD identified along the frailty continuum, and aims to reveal congruence and gaps between evidence and practice.

2 | METHOD

This study was housed within a larger study of collaboration between the health and developmental services sectors in Ontario, Canada (Martin et al., 2020), and was approved by the Lakehead University Research Ethics Board and the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

2.1 | Context

In Ontario, significant investments have been made in community-based health and developmental services and supports—both of which may be accessed by those with IDD. Home care services include, but are not limited to, assessment, referral, nursing, therapy, case management and personal supports. Developmental services are aimed at adults with IDD, they are community-based and include residential and employment supports, as well as those related to recreation, day programs and respite. In the larger study, the participating home care agency and a developmental services agency were

both large organizations (e.g. hundreds of staff and clients) located in the province's most populous metropolitan area.

These two organizations partnered to support 26 older adults with IDD (i.e. 45 years or older) identified as along the frailty continuum based on the Home Care-Intellectual and Developmental Disability Frailty Index (HC-IDD FI; McKenzie, Ouellette-Kuntz, & Martin, 2015). The HC-IDD FI is based on items in the RAI-Home Care assessment instrument (Morris et al., 2009), which is used in Ontario's home care sector.

2.2 | Document review

In Ontario, service agencies are required to develop 'individual support plans' for each person that outline: preferences and needs; short- and long-term goals; expected outcomes of said goals; persons or supports required; and the amount of resources allocated (Quality Assurance Measures, 2011). However, this was the first time the developmental services agency wherein the study was situated had engaged in care planning with another sector with a focus on frailty. Thus, two coordinators (hired by the developmental services agency) developed and implemented integrated care plans for each of the 26 individuals as part of the larger project. The care plans recorded information related to the issues contributing to frailty status (e.g. mobility, communication and behaviour changes), in addition to short- and long-term goals to be acted upon by providers in both sectors, as well as informal supports. The care plans existed as living documents that were regularly updated over the course of the year-long project (e.g. comments on outcomes related to identified goals). A total of 23 integrated care plans were reviewed, as three individuals had incomplete documentation (left the agency or passed away). Sixteen care plans focused on individuals who were pre-frail, with the remaining seven on individuals identified as frail.

The care plans were anonymized and shared with the research team. Coding was based on the frailty consensus statement's principles and recommendations, and completed primarily by one member of the research team (a subset of care plans were coded by a second team member to ensure agreement). Only five of the seven recommendations from the statement were considered for coding: the first recommendation ('Frailty must be considered earlier') was not coded as only persons aged 45 years and older were included in the sample; the last recommendation ('The evidence base must be grown') also was not coded, as the care plans were part of a larger study aiming to increase the evidence base.

3 | RESULTS

The integrated care plans often contained goals, actions and outcomes relevant to multiple principles and recommendations from the statement. Which principles and recommendations emerged differed from one individual to the next, depending on the areas of concern identified.

Among the two principles, using a person-centred approach was most often reflected in the care plans—this was observed in 26.1% of all plans. Prioritization of ageing in place was observed less frequently and was found in 17.4% of plans.

In terms of the five recommendations coded in the integrated care plans, there was the most evidence for intersectoral collaboration (69.5% of plans), followed by a focus on improvement and maintenance as goals of support (65.2% of plans). While some plans did have a focus on safety and planning for the future, these were much less common (30.4% and 26.1%, respectively). Least common was a goal, action or outcome related to the needs of caregivers, which was identified in only 8.7% of plans (Figure 1). No new themes or ideas emerged during coding.

Care plans varied across individuals in terms of outcomes and the implementation of the principles and recommendations. For example, Jessica (pseudonym) expressed her preference to live at home and do exercises she enjoyed. Though mobility in bed and within her home, and a loss of strength were flagged as issues prior to the implementation of her exercise plan, regular practice led to Jessica getting in and out of bed with minimal support. This exercise plan tailored to Jessica's desires touched on both principles of a person-centred approach and ageing in place as well as the recommendation for improvement and maintenance. Intersectoral collaboration was also mentioned, as her family doctor, direct support worker and occupational therapist worked closely to ensure the exercises were done and modified as needed. In contrast, the care plan for Michael (pseudonym) noted decline in multiple physical and social domains,

with an increase in recent hospital visits and fall frequency. Michael began and successfully transitioned into a long-term care facility, with support and communication between the different sectors noted as an important lesson. He and his family both identified his preferences for care and placement during his transition while working with the multiple sectors. It was also noted that there was no increase in fall frequency or mobility-related issues once in long-term care. Thus, Michael's plan touched on having a person-centred approach, intersectoral collaboration, and improvement and maintenance, but not ageing in place as he transitioned out of his original community.

4 | DISCUSSION

This study identified the extent to which the principles and recommendations of an international consensus statement were present in existing integrated care plans to support older adults with IDD identified along the frailty continuum. Overall, the results provide some support for the face validity and applicability of the international consensus statement.

The lack of emergence of additional themes regarding actions for frailty in the care plans shows preliminary evidence of the validity of the interrelated principles and recommendations of the statement and suggests that the statement is comprehensive. That not every principle and recommendation was found in every care plan warrants further study. Documentation practices or lack of

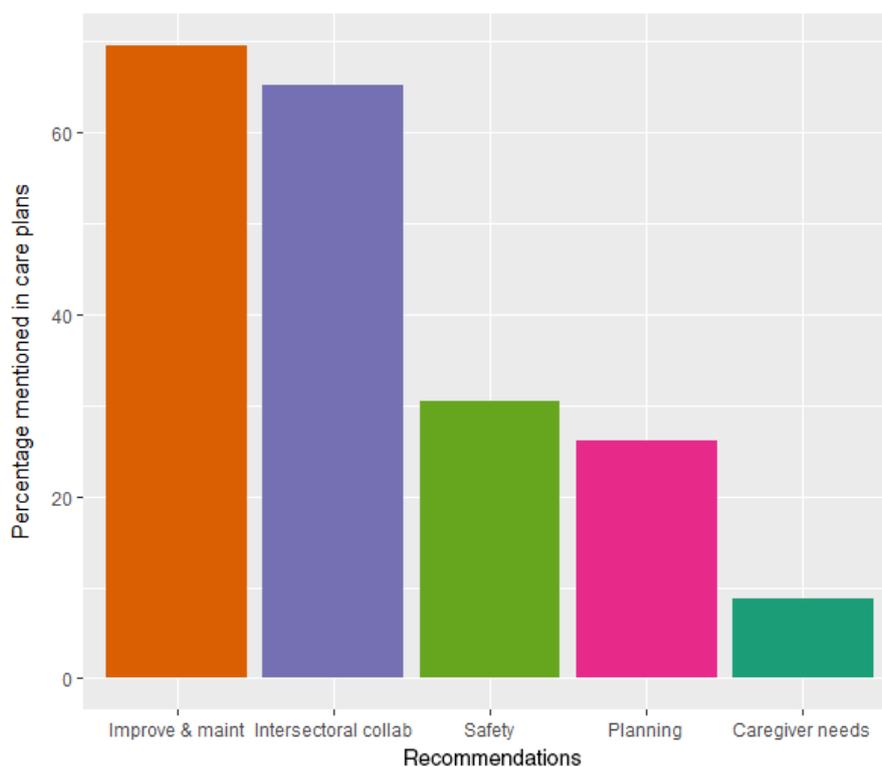


FIGURE 1 Percentages of integrated care plans ($n = 23$) that mentioned the five coded consensus statement recommendations. Categories are not mutually exclusive [Colour figure can be viewed at wileyonlinelibrary.com]

consideration may play a role; for example, where the needs of caregivers mentioned the least often because paid caregivers/staff do not think about their own needs, or do they simply not document them? Additionally, certain recommendations may also be more relevant at certain points along the frailty continuum based on an individual's circumstances. In addition to the small number of care plans in this study, the plans themselves lacked details that could provide insight as to why some recommendations were mentioned less often. Standardization of documentation could help reveal whether and how issues were considered as well as when they became a priority, or why they never did.

Evidence supporting the importance of both core principles was found in the care plans, though use of a person-centred approach was more frequently observed than one prioritizing ageing in place. Ontario enacted the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act in 2008. Among other things, the Act promotes the use of person-centred (or person-directed) approaches to planning supports in the developmental services sectors. The province has also released a guide to aid in person-directed planning efforts (Person-Directed Planning & Facilitation Guide, 2013; Social Inclusion Act, 2008). Two years after the act was implemented, the Quality Assurance Measures (QAM) Regulation was appended to outline how service agencies should address measures of daily life for adults with IDD, including requiring that funded agencies develop individual care plans that address the person's goals, preferences and needs (Quality Assurance Measures, 2011). Given the legislative and regulatory context in Ontario's developmental services sector, the frequent mention of a person-centred approach was not unexpected. Also, since the partnership between the home care and developmental services agency was, in part, in response to a desire to keep people who are frail in their homes and out of long-term care (e.g. Ministry of Health funded residential facilities providing nursing care, also called nursing homes), ageing in place may have been assumed and not mentioned. The policy and practice environment in which this study was conducted favours these principles.

As the larger study focused on the partnership between the home care and developmental services agencies, the attention placed on intersectoral collaboration in the care plans was anticipated. Many goals in the care plans related to improvement and maintenance often focused on physical and social deficits, echoing other studies documenting goals for patients without IDD receiving palliative care (Schellinger et al., 2018).

It is important to consider why the recommendation to address the needs of formal and informal caregivers was rarely considered in the care plans. A large portion of goals for patients without IDD receiving palliative care have been found to be physically or medically related, with only six per cent of patient's goals focussed on support for family and caregivers (Schellinger et al., 2018). Studies among other groups have found patient preferences relating to psychosocial domains, including end of life care, to be systematically undocumented in medical charts (Langewitz et al., 2009; Yung et al., 2010).

Furthermore, certain preferences for care may not be reported due to a lack of proper documentation methods for the patient across care settings and potential interpretation inconsistencies of patient-spoken preferences (Foglia et al., 2019; Yung et al., 2010). While individuals in the current study did not live with their informal caregivers, it remains important to consider how their age-related health decline affects those who play a role in supporting them in both direct and indirect ways: aiding improvement and maintenance; ensuring safety; and engaging in advanced care planning and intersectoral collaboration to benefit the individual. Regardless of where the individual lives, professionals coordinating the development of support plans should be alerted to the need to support formal and informal caregivers as well. Future work is needed to better identify the needs of informal and formal caregivers in this context, and how home care and developmental services agencies can best address those needs.

Limitations of the current study include the lack of standard documentation and the limited sample size. Despite the QAM regulation requiring agencies to develop individual support plans, the developmental services agency did not have a suitable care plan that could be utilized in this project, and the creation of one required ongoing revision. It is likely that not every action or outcome was documented by agency staff, either due to staff shift changes or simply forgetting to translate conversations into the care plan. As such, the resulting numbers should be considered minimums. Finally, the low number of care plans examined prevented further statistical analyses to identify whether certain messages were mentioned significantly more and if there were differences by frailty status.

While this study shows that the international consensus statement is applicable to support planning in the context of older adults with IDD who are frail, there is a need for additional work to look at whether adoption of the principles and recommendations lead to better outcomes over the short and longer term. Further work should also examine how to support those working in the developmental services sector to ensure documentation of said outcomes in care plans.

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REFERENCES

- Bronskill, S., Carter, M., Costa, A., Esensoy, A., Sudeep, G., Gruneir, A., Henry, D., Hirdes, J., Jaakkimainen, L., Poss, J., & Wodchis, W. (2010). *Ageing in Ontario: an ICES chartbook of health service use by older adults - technical report*. Institute for Clinical Evaluative Sciences.
- Coppus, A. M. W. (2013). People with intellectual disability: What do we know about adulthood and life expectancy? *Developmental Disabilities Research Reviews*, 18, 6–16.

- Foglia, M. B., Lowery, J., Sharpe, V. A., Tompkins, P., & Fox, E. (2019). A comprehensive approach to eliciting, documenting, and honoring patient wishes for care near the end of life: The Veterans Health Administration's life-sustaining treatment decisions initiative. *The Joint Commission Journal on Quality and Patient Safety*, 45(1), 47–56. <https://doi.org/10.1016/j.jcjq.2018.04.007>
- Langewitz, W. A., Loeb, Y., Nübling, M., & Hunziker, S. (2009). From patient talk to physician notes—Comparing the content of medical interviews with medical records in a sample of outpatients in Internal Medicine. *Patient Education and Counseling*, 76(3), 336–340. <https://doi.org/10.1016/j.pec.2009.05.008>
- Lavis, J. N., Posada, F. B., Haines, A., & Osei, E. (2004). Use of research to inform public policymaking. *The Lancet*, 364(9445), 1615–1621. [https://doi.org/10.1016/S0140-6736\(04\)17317-0](https://doi.org/10.1016/S0140-6736(04)17317-0)
- Martin, L., Deck, E., Barabash, T., & Ouellette-Kuntz, H. (2020). Intersectoral collaboration in the context of supporting adults with intellectual and developmental disabilities who are frail. *Research and Practice in Intellectual and Developmental Disabilities*, 7(1), 26–38.
- 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.
- Morris, J. N., Fries, B. E., Bernabei, R., Steel, K., Ikegami, N., Carpenter, I., Gilgen, R., DuPasquier, J. N., Frijters, D., Henrard, J. C., Hirdes, J. P., Belleville-Taylor, P., Berg, K., Björken, M., Gray, L., Hawes, C., Ljunggren, G., Nonemaker, S., Phillips, C., & Zimmerman, D. (2009). *Home care (HC) assessment form and user's manual*. 9.1. interRAI.
- 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(1), 35–42. <https://doi.org/10.1111/jar.12499>
- Ouellette-Kuntz, H., Martin, L., & McKenzie, K. (2015). Chapter Six—A Review of Health Surveillance in Older Adults with Intellectual and Developmental Disabilities. In C. Hatton, & E. Emerson (Eds.), *International review of research in developmental disabilities* (Vol. 48, pp. 151–194). Academic Press.
- Ouellette-Kuntz, H., Martin, L., & McKenzie, K. (2016). Population aging and intellectual and developmental disabilities: Projections for Canada. *Journal of Policy and Practice in Intellectual Disabilities*, 13(4), 254–260.
- Person-Directed Planning and Facilitation Guide (2013). *Person-directed planning and facilitation guide*. Ministry of Community and Social Services. https://www.mcscs.gov.on.ca/documents/en/mcscs/publications/developmental/Person_DirectedPlanning.pdf
- Quality Assurance Measures (2011). *Ontario regulation: Quality assurance measures, no. 299/10*. Government of Ontario. Retrieved from <https://www.ontario.ca/laws/regulation/100299>
- Schellinger, S. E., Anderson, E. W., Frazer, M. S., & Cain, C. L. (2018). Patient self-defined goals: Essentials of person-centered care for serious illness. *American Journal of Hospice and Palliative Medicine®*, 35(1), 159–165. <https://doi.org/10.1177/1049909117699600>
- Social Inclusion Act (2008). *Services and supports to promote the social inclusion of persons with Developmental Disabilities Act, c. 14*. Government of Ontario. Retrieved from <https://www.ontario.ca/laws/statute/08s14>
- Wang, S., Moss, J. R., & Hiller, J. E. (2006). Applicability and transferability of interventions in evidence-based public health. *Health Promotion International*, 21(1), 76–83. <https://doi.org/10.1093/heapro/dai025>
- Yung, V. Y., Walling, A. M., Min, L., Wenger, N. S., & Ganz, D. A. (2010). Documentation of advance care planning for community-dwelling elders. *Journal of Palliative Medicine*, 13(7), 861–867. <https://doi.org/10.1089/jpm.2009.0341>

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