

How to best support individuals with IDD as they become frail: An international consensus statement [version 1; 1 December 2017]

This consensus statement and the full methodology of its development were published in the *Journal of Applied Research in Intellectual Disabilities* and can be found here:

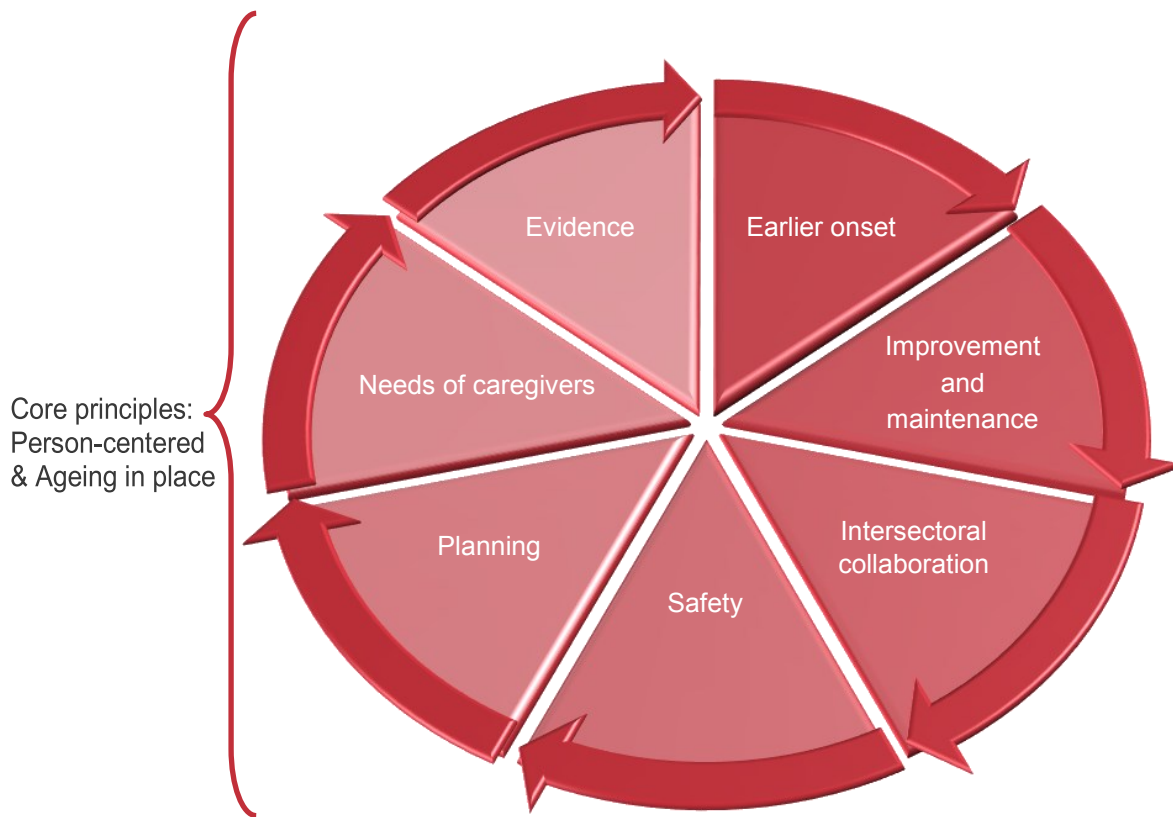
Ouellette-Kuntz, H., Martin, L., Burke, E., McCallion, P., McCarron, M., McGlinchey, E.,... Temple, B. (2018). How to best support individuals with IDD as they become frail: Development of a consensus statement. *Journal of Applied Research in Intellectual Disabilities*, <https://doi.org/10.1111/jar.12499>.

Persons with intellectual and developmental disabilities (IDD) are increasingly living well into old age; however there is higher prevalence and earlier onset of age-related chronic health conditions¹ and mortality². Multi-morbidity is notable in this population with unique patterns that differ considerably from the general population.^{3,4} Since the late 1990s, policy makers, service providers and researchers have become more and more concerned about the size and changing needs of the ageing population with IDD.⁵⁻⁷ More recently, clinicians and researchers have sought to better characterise ageing related needs of this population through the concept of frailty – a multi-dimensional state of vulnerability, with cognitive, social, psychological, and biological deficits, as well as environmental aspects associated with ageing and adverse outcomes (e.g. falls, hospitalisation, institutionalisation, mortality).^{8,9}

Research related to frailty among adults with IDD is relatively new, and to date has only been conducted by three research teams internationally, who have largely focused on measuring and developing measures of frailty for use in this population.¹⁰ No studies have examined the effectiveness of interventions specifically addressing frailty in individuals with IDD. In the absence of a body of research to inform best practice, an international consultation was undertaken with the aim of producing *an international consensus statement regarding the best approaches to supporting individuals with IDD as they become frail*.

The purpose of this statement is to:

- **promote awareness** of frailty in the field of IDD, and
- **guide support/care planning** considerations when an individual is identified as frail or pre-frail.



Two core principles underlie the recommendations in this Statement.

A person-centered approach to planning is used. Person-centered approaches are the foundation on which supports and services are planned in the field of IDD.^{11,12} Given the multitude and complexity of issues experienced by pre-frail and frail individuals, there is a risk of focusing on distinct deficits, rather than on the person as a whole and what he/she wants. 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.

Ageing in place is a priority. “Ageing in place”¹³ means being able to remain in one’s current residence even when faced with increasing need for support due to decline in health or life changes. The desire to live in the community as independently as possible and for as long as possible is one that has been expressed by individuals (with and without IDD), families, caregivers, and governments around the world.^{14,15} Action on pre-frailty and frailty must also support ageing in place through the use of home-based health services, a focus on environmental accommodations, attention to prevention, and greater use of supportive technologies.¹⁶

Recommendations include seven essential and interconnected considerations for action.

1. Frailty must be considered earlier than in the general population.

Premature ageing among persons with IDD is well-established.¹⁷⁻¹⁹ More recently, research has shown that persons with IDD experience higher rates of frailty,²⁰ with earlier onset than in the general population.²¹⁻²³ Research has revealed that frailty should be monitored in all adults with IDD beginning at 40 years of age, and possibly earlier in some sub-groups (e.g., Down syndrome), given that they accumulate frailty deficits more quickly.²⁴

2. Improvement and maintenance are viable goals.

Once identified as pre-frail or frail, it is important to recognise that there exists both a risk of future decline and an opportunity for improvement.^{24,25} Sudden, rapid decline although more often seen among those who are frail, is also a risk for those who are pre-frail. Similarly, while improvement and return to previous function is more likely among those who are pre-frail, improvement and maintenance (i.e., stability) are viable goals for those identified as frail. Planning must take into account both risks and opportunities.

3. Intersectoral collaboration is needed to coordinate comprehensive, multidisciplinary assessments and actions.

Frailty is complex, involving a number of deficits within and across multiple domains. Documented challenges faced by persons with IDD when interacting with healthcare providers complicate assessments. A comprehensive multidisciplinary assessment of functioning, physical and mental health (including medications), behaviour, social context (including life events), capacity for decision-making, and available supports is needed –

with special consideration of how these interact with one another. When an individual is identified as pre-frail or frail, intersectoral collaboration is also needed to review existing arrangements and identify new, additional, or different supports, interventions and treatments to meet his/her needs.²⁶ Advocacy, care coordination, case management and planned follow-up are required to ensure that plans are implemented, actions are monitored, and supports/services are responsive to new and emerging needs.^{27,28}

4. Safety is a priority.

Adults with IDD who are pre-frail or frail experience various deficits that on their own, and in combination with one another, affect health, activities, and functioning. There is a need to be proactive to ensure that the person is safe and feels secure in his/her environment. A comprehensive risk assessment is needed, with special attention paid to the individual's right to make choices and take risks, while optimizing health and safety with implementation of relevant actions.²⁹⁻³²

5. Planning for the future is important.

When identified as pre-frail or frail, it is important to help the person engage in advanced care planning, at the earliest possible stage and on a continuous basis. This should be done in conjunction with the multidisciplinary assessment and the direct involvement of key carers. Documentation of the person's preferences and wishes for the future is essential, and should consider living arrangements, financial security, supported decision-making, advanced care directives.³³⁻³⁵

When frail, however, the focus may need to shift to include implementation of documented plans.

6. Informal and formal caregivers also have needs. Adults with IDD have complex and multiple needs that often necessitate support from both informal and formal carers. As the person's needs emerge and/or become more complex, resulting in identification as pre-frail or frail, informal and formal carers' needs also increase and become more complex. Carers should receive the knowledge, skills, or assistance needed to support the individual.³⁶⁻³⁸ A discussion with carers about their needs is warranted, with attention paid to emotional and spiritual support, as appropriate, and respite.

7. The evidence base must be grown. The study of frailty in the field of IDD is relatively new. As a result, the body of literature in this area is small and limited in scope.¹⁰ In order to inform best practices, evidence of effectiveness of specific interventions to address the needs of frail or pre-frail individuals with IDD is needed. Intervention research should be prioritized to build the body of evidence that will lead to better support for persons with IDD as they become frail, and eventually inform best practice.

Authors of this Statement

The statement represents the summary of opinions of an international expert panel, which was based on comprehensive and current information. Our expert international panel on frailty in IDD included:

Canada: Dr. H el ene Ouellette-Kuntz (Public Health Sciences, Queen's University), Dr. Lynn Martin (Health Sciences, Lakehead University), Dr. Shahin Shooshtari (Community Health Sciences, University of Manitoba), and Dr. Bev Temple (Nursing, University of Manitoba).

The Netherlands: Josje Schoufour (Epidemiology, Erasmus Medical Center).

Ireland: Dr. Eilish Burke (Nursing and Midwifery, Trinity College Dublin), Prof. Mary McCarron (Health Sciences, Trinity College Dublin), and Dr. Eimear McGlinchey (Nursing and Midwifery, Trinity College Dublin).

Sweden: Magnus Sandberg (Health Sciences, Lund University).

USA: Prof. Philip McCallion (Social Work, Temple University & Nursing and Midwifery, Trinity College Dublin).

Glossary

Advanced care directives: Advanced care directives (also known as a living will or healthcare proxy) are captured in a document that specifies what actions should be taken or who is authorized to make decisions on a person's behalf if he/she is no longer able to make decisions for him/herself because of illness or incapacity.

Advanced care planning: Advanced care planning is a process where people consider the various options related to future health care decisions and develop a verbal or written plan (e.g. advanced care directives) of what care they would want (or not want) at the end of life.

Ageing in Place: Ageing in place means being able to continue to live in one's current residence even when faced with increasing need for support due to decline in health or life changes. Achieving ageing in place recognises the person's right to choice, as well as the need to provide supports and to hear the concerns of family and other caregivers.

Intersectoral collaboration: Intersectoral collaboration has been defined as: "A recognized relationship between part or parts of different sectors of society which has been formed to take action on an issue to achieve health outcomes or intermediate health outcomes in a way which is more effective, efficient or sustainable than might be achieved by the health sector acting alone."³⁹

Key carer: The key carer is the primary point of support for the person with IDD; it can be a family member or paid worker. The key carer focuses on advocating across systems for the person with IDD to access needed services.

Multidisciplinary: A multidisciplinary team has been defined by the World Health Organization as "consist[ing] of members of different disciplines, involved in the same task (assessing people, setting goals and making care recommendations) and working alongside each other, but functioning independently."⁴⁰

Multimorbidity: Multimorbidity refers to the co-occurrence of at least two diseases or conditions, in addition to the IDD, which may negatively influence daily functioning.⁴¹

Person-Centred Approach: A person-centered approach is one that focuses on the person's strengths, goals, and abilities; promotes and facilitates opportunities to make meaningful choices; and involves collaboration with natural supports (e.g., family, friends).⁴²

Prevention: Prevention refers to any action that helps to avoid or delay negative outcomes, such as social isolation, injury, disability and disease.

Statement References

1. Burke, E., McCarron, M. & McCallion, P. (2014). Advancing years, different challenges: Wave 2 IDS-TILDA: Findings on ageing of people with an intellectual disability: An intellectual disability supplement to the Irish Longitudinal Study on Ageing. Dublin: Retrieved from http://www.idstilda.tcd.ie/assets/pdf/Wave_2_Report_October_2014.pdf.
2. McCarron, M., Carroll, R., Kelly, C. & McCallion, P. (2015). Mortality rates in the general Irish population compared to those with an intellectual disability from 2003 to 2012. *Journal of Applied Research in Intellectual Disabilities*, 28(5), 406-413.
3. McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Carroll, R. & McCallion, P. (2013). Patterns of multimorbidity in an older population of persons with intellectual disability: Results from the intellectual disability supplement to the Irish longitudinal study on aging (IDS-TILDA). *Research in Developmental Disabilities*, 34(1), 521-527.
4. Lauer, E. & McCallion, P. (2015). Mortality of people with intellectual and developmental disabilities from select U.S. States. *Journal of Applied Research in Intellectual Disabilities*, 28(5), 394-405.
5. Ouellette-Kuntz, H., Martin, L., & McKenzie, K. (2015). A review of health surveillance in older adults with intellectual and developmental disabilities. *International Research Review in Developmental Disabilities*, 48, 151-194.
6. McGinley, J. (2016). From nonissue to healthcare crisis: A historical review of aging and dying with an intellectual and developmental disability. *Intellectual and Developmental Disabilities*, 54(2), 151-156.
7. World Health Organization. (2000). *Ageing and Intellectual Disabilities - Improving Longevity and Promoting Healthy Ageing: Summative Report*. Geneva: WHO.
8. Clegg, A., Young, J., Iliffe, S., Rikkert, M.O. & Rockwood, K. (2013). Frailty in elderly people. *The Lancet*, 381(9868), 752-762.
9. Gale, C., Cooper, C. & Sayer, A. (2015). Prevalence of frailty and disability: Findings from the English Longitudinal Study of Ageing. *Age and Ageing*, 44(1), 162-165.
10. McKenzie, K., Martin, L. & Ouellette-Kuntz, H. (2016). Frailty and intellectual and developmental disabilities: A scoping review. *Canadian Geriatrics Journal*, 19(3), 103-112.
11. Claes, C., Van Hove, G., Vandervelde, S., van Loon, J. & Schalock, R. (2010). Person-centered planning: Analysis of research and effectiveness. *Intellectual and Developmental Disabilities*, 48(6), 432-453.
12. Taylor, J. & Taylor, J. (2013). Person-centered planning: Evidence-based practice, challenges, and potential for the 21st century. *Journal of Social Work in Disability & Rehabilitation*, 12(3), 213-235.
13. Greenfield, E.A. (2012). Using ecological frameworks to advance a field of research, policy and practice on aging-in-place initiatives. *The Gerontologist*, 52, 1-12.
14. Bigby, C. (2010). A five-country comparative review of accommodation support policies for older people with intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 3-15.
15. Ball, M.M., Perkins, M.M., Whittington, F.J., Connell, B. R., Hollingsworth, C., King, S.V., Elrod, C.L., Combs, B.L. (2004). Managing decline in assisted living: The key to aging in place. *The Journals of Gerontology: Series B*, 59(4), S2-2-S212.
16. Vasunilashorn, S., Steinman, B.A., Liebig, P.S. & Pynoos, J. (2012). Aging in place: Evolution of a research topic whose time has come. *Journal of Aging Research*, p. 6. <https://doi.org/10.1155/2012/120952>.
17. Béange, H. (2002). Epidemiological issues. In V. P. Prasher, & M. P. Janicki, (Eds.), *Physical health of adults with intellectual disabilities* (pp. 1-20). Oxford, UK: Blackwell Publishing LTD.
18. Lifshitz, H., & Merrick, J. (2004). Aging among persons with intellectual disability in Israel in relation to type of residence, age, and etiology. *Research in Developmental Disabilities*, 25(2):193-205.
19. Stax, T.E., Luciano, L., Dunn, A.M. & Quevedo, J.P. (2010). Aging and developmental disability. *Physical Medicine & Rehabilitation Clinics of North America*, 21(2): 419-427.
20. Schoufour, J.D., Mitnitski, A., Rockwood, K., Evenhuis, H.M. & Ehteld, M.A. (2013). Development of a frailty index for older people with intellectual disabilities: Results from the HA-ID study. *Research in Developmental Disabilities*, 34(5):1541-1555.
21. Marks, B., Sisirak, J., & Hsieh, K. (2008). Health services, health promotion, and health literacy: Report from the state of the science in aging and developmental disabilities conference. *Disability and Health Journal*, 1(3), 136-142.
22. Ouellette-Kuntz, H., Martin, L., & McKenzie, K. (2017). The risk of reinstitutionalization: Examining rates of admission to long-term care among adults with intellectual and developmental disabilities over time. *Journal of Policy and Practice in Intellectual Disabilities*, 14(4), 293-297.
23. Martin, L., Ouellette-Kuntz, H., & McKenzie, K. (2017). Care in the community: Home care use among adults with intellectual and developmental disabilities over time. *Journal of Policy and Practice in Intellectual Disabilities*, 14(3), 251-254. <https://doi.org/10.1111/jppi.12171>.
24. Ouellette-Kuntz, H., Martin, L., & McKenzie, K. (2018). Rate of deficit accumulation in home care users with intellectual and developmental disabilities. *Annals of Epidemiology*, 28(4), 220-224.

25. Martin, L., Ouellette-Kuntz, H., & McKenzie, K. (2017). Once frail, always frail? Frailty transitions in home care users with intellectual and developmental disabilities. *Geriatrics & Gerontology International*, 18, 547-553. <https://doi.org/10.1111/ggi.13214>.
26. Calgary Region Community Board Persons with Developmental Disabilities. (2012). *Supports and Services for Older Adults with Developmental Disabilities Study* (pp. 1-84, Rep.). Alberta.
27. Xie, C., Hughes, J., Challis, D. & Cambridge, P. (2008). Care management arrangements in services for people with intellectual disabilities: Results of a national study. *Journal of Applied Research in Intellectual Disabilities*, 21, 156-167.
28. Bishop, K.M., Hogan, M., Janicki, M.P., Keller, S.M., Lucchino, R., Mughal, D.T., Perkins, E.A., Singh, B.K., Service, K., Wolfson, S. and the Health Planning Work Group of the National Task Group on Intellectual Disabilities and Dementia Practice (2015). Guidelines for dementia-related health advocacy for adults with intellectual disability and dementia. *Intellectual and Developmental Disabilities*, 53(1), 2-29.
29. Hsieh, K., Rimmer, J. & Heller, T. (2012). Prevalence of falls and risk factors in adults with intellectual disabilities. *American Journal on Intellectual and Developmental Disabilities*, 117(6), 442-454.
30. Willgoss, T., Yohannes, A. & Mitchell, D. (2010). Review of risk factors and preventative strategies for fall-related injuries in people with intellectual disabilities. *Journal of Clinical Nursing*, 19(15-16), 2100-2109.
31. Samuels, R. & Chadwick, D. (2006). Predictors of asphyxiation risk in adults with intellectual disabilities and dysphagia. *Journal of Intellectual Disability Research*, 50(5), 362-370.
32. Thacker, A., Abdelnoor, A., Anderson, C., White, S. & Hollins, S. (2008). Indicators of choking risk in adults with learning disabilities: A questionnaire survey and interview study. *Disability and Rehabilitation*, 30(15), 1131-1138.
33. Taggart, L., Truesdale-Kennedy, M. Ryan, A. & McConkey, R. (2012). Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. *Journal of Intellectual Disabilities*, 16(3), 217-234.
34. Heller, T. & Caldwell, J. (2006). Supporting aging caregivers and adults with developmental disabilities in future planning. *Mental Retardation*, 44(4), 189-202.
35. Ritchie, C., Roth, D. & Allman, R. (2011). Living with an aging parent "It was a beautiful invitation". *Journal of the American Medical Association*, 306(7), 746-753.
36. Daly, L., Sharek, D., DeVries, J. Griffiths, C., Sheerin, F., McBennett, P., Higgins, A. (2015). The impact of four family support programmes for people with a disability in Ireland. *Journal of Intellectual Disabilities*, 19(1), 43-50.
37. Lunsy, Y., Robinson, S., Blinkhorn, A., & Ouellette-Kuntz, H. (2017). Parents of adults with intellectual and developmental disabilities (IDD) and compound caregiving responsibilities. *Journal of Family and Child Studies*, 26(5), 1374-1379.
38. Northway, R. (2015). An age-old problem? *Journal of Intellectual Disabilities*, 19(2): 101-2.
39. World Health Organization. (1993). *Health Promotion Glossary*. 1-26. Retrieved from: <http://www.who.int/healthpromotion/about/HPR%20Glossary%201998.pdf?ua=1>
40. World Health Organization. (2004). A glossary of terms for community health care and services for older persons. 15. Retrieved from: http://www.who.int/kobe/centre/ageing/ahp_vol5_glossary.pdf.
41. Hermans, H., & Evenhuis, HM. (2014). Multimorbidity in older adults with intellectual disabilities. *Research in Developmental Disabilities*, 35 (4), 776-783.
42. Martin, L., & Ouellette-Kuntz, H. (2011). Identifying the core elements of person-centered/directed planning. Kingston, ON: Multidimensional Assessment of Providers and Systems.



MAPS

MULTIDIMENSIONAL ASSESSMENT
OF PROVIDERS AND SYSTEMS

Contact Information:

Hélène Ouellette-Kuntz
191 Portsmouth Avenue, Kingston, Ontario, Canada, K7M 8A6
Phone: (613) 548-4417 x. 1198
Fax: (613) 548-8135
Email: helene.kuntz@queensu.ca

