A FOCUS ON FRAILTY and AGING

Frailty and IDD: What do we know? Where do we go?

Summary of Plenary Address by Hélène Ouellette-Kuntz & Lynn Martin at the IASSIDD Health SIRG Conference held in Belfast, Northern Ireland (June 19 & 20, 2017)

Frailty is a multi-dimensional state of vulnerability, with cognitive, social, psychological, biological and environmental aspects associated with aging. In the general population, frailty has been shown to be associated with adverse outcomes including institutionalization, hospitalization, and mortality. This plenary address described the context in which frailty is emerging as an important concept to the field of intellectual and developmental disabilities (IDD) highlighting the importance of measuring frailty and understanding how best to support frail adults with IDD.

The well-documented higher level of health needs and health care disparities faced by adults with IDD combined with the knowledge of increased life expectancy, the recognition of the growing numbers of older adults, and the earlier onset of aging has resulted in higher and earlier use of aging-related services by adults with IDD. These issues were illustrated using results from studies conducted in Ontario, Canada.

To measure frailty among adults with IDD, the accumulation of deficits approach is recommended over the phenotype approach which tends not to be multi-dimensional and which does not necessarily reflect decline or change. To date, only four research groups around the world have published research on frailty among adults with IDD. These groups are based in the Netherlands, Austria, Taiwan and Canada. Validated measures exist which characterize adults with IDD as frail, pre-frail, and robust/non-frail. These measures have demonstrated that among adults with IDD, frailty predicts care intensity, survival, and institutionalization.

Reports of the prevalence of frailty among adults with IDD vary widely depending on the measure used and the population studied. Validated measures specific to IDD, reveal that across the adult lifespan, just over 1/3 are characterized as pre-frail or frail. When only older adults are included (e.g. 50+ years), the proportion affected reaches 70%.

Studies consistently report an association between frailty and Down syndrome (DS). Other factors that may be associated with frailty among adults with IDD include mental illness, health conditions, functional impairment, cognitive impairment and living arrangement. Sex and urban/rural living do not appear to be associate with frailty in this population. Our recent work confirms that frailty among adults with IDD is changeable (including improvement) and that the rate at which individuals accumulate frailty deficits is variable. As those 40 years and older, or with DS or who are pre-frail are more likely to accumulate deficits faster, they should be monitored closely.

The address concluded with a call to action in order to prevent, delay and reverse frailty. Participants were invited to join a workshop to contribute to the preparation of a consensus statement regarding best approaches to supporting individuals with IDD as they become frail.

In this newsletter, we bring you updates on aging and frailty-related projects, key findings from recent publications and information on upcoming events.

Hélène and Lynn

Support for the work presented was provided by the Ontario Ministry of Community and Social Services and Reena.

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) is a large scale nationally representative study of people with an intellectual disability aged 40 years and over in Ireland and the first study in the world to have been conducted in tandem with a general ageing study. Each data collection point is a three years wave. Currently Waves 1, 2 & 3 are complete with the Wave 3 report due later this year (www.idstilda.tcd.ie).

Respondents reported experiencing good health but there were significant concerns in terms of polypharmacy, mental health concerns, dementia, epilepsy, constipation, arthritis, osteoporosis, urinary incontinence, falls, cancer, and thyroid disease. Women with intellectual disability had higher risks for many diseases, both when compared to men with intellectual disability and to women in the general population. Nine out of 10 participants (91%) were taking at least one (prescription or non-prescription), medicine and almost 7 in 10 women presented with evidence of undiagnosed osteoporosis (69.4%). Participants reported that they hardly ever engaged in vigorous physical activity and there were significant visual problems identified, and at a much younger age than the general population. Prevalence reported for mental health and emotional problems was also greater than in the general population. Dementia in persons with Down syndrome doubled over the three year period between Wave 1 and 2.

Family networks of older people with intellectual disability in Ireland looked very different to that of the general population- older people with intellectual disability are generally single/unmarried and without any children or grandchildren. They are far more reliant on siblings and extended family to provide family networks, especially as they age and parents pass away. In addition, most family members of older people with intellectual disability lived in different neighbourhoods than their relative with intellectual disability.

Greater longevity among people with an intellectual disability is to be celebrated and as people with intellectual disabilities live increasingly in the community and access community based health care services, the results emanating from IDS-TILDA challenges those health care providers to better understand and prepare for their unique health needs thus ensuring all people with intellectual disability enjoy healthy later years.

CANADA: Successful aging – frailty, transition and inclusion into senior services

There is a need to consider a much broader range of service options for adults with IDD, largely borne out by the volume of unmet needs of those living with families, the research on aging and frailty, and the number of individuals living in inappropriate or precarious housing situations. The Ontario (Canada) Ministry of Community and Social Services recently funded a project led by Reena and Mary Centre Archdiocese of Toronto to examine frailty, transitions, and use of aging services. This project focuses on updating the “Aging with a Developmental Disability – Transition Guide for Caregivers”, originally developed by the Ontario Partnership on Aging and Developmental Disabilities in 2005, and using the frailty index. Upon identification of frailty status, promising practices to support pre-frail and frail individuals with IDD will be implemented by health and developmental services providers to better support them as they live and age in the community.

INTERNATIONAL: CONSENSUS STATEMENT

Research related to frailty among adults with IDD is relatively new, and currently only being conducted by three research teams internationally. While all studies have reported higher rates of frailty and presence of frailty at earlier ages than in the general population, there is limited research of effectiveness of specific interventions on frailty among the population of adults with IDD. As such, there is insufficient evidence to inform a clinical guideline. However, there exists sufficient expertise to develop a consensus statement on action to take when someone is identified as being pre-frail or frail. Look for the link to a survey to come later in September!

Recent and Upcoming Publications

2016-2018 JPPID Series on Aging and Frailty

Through the Health Care Access Research and Developmental Disabilities (or H-CARDD) project, funded by the Ontario Ministry of Health and Long-term Care, Drs. Hélène Ouellette-Kuntz and Lynn Martin led a program of research focused on a number of issues related to aging and frailty among adults with IDD in Ontario, Canada.

Their work showed that the number of adults with IDD in Ontario (Canada) aged 45 to 84 years is expected to increase by approximately 20% by 2020. They also found that Ontarians with IDD experience much higher rates of frailty at much earlier ages than the general population: similar rates of frailty were seen among adults with IDD at age 50 as for adults without IDD at age 80. The use of home care services by adults with IDD was approximately three times higher than in the general population without IDD. Within the subset of home care users with IDD, the largest proportion were 45 to 54 years of age, whereas the majority of home care without IDD are 75 years of age or more. The rate of admission to long-term care services was up to nine times higher among adults with IDD, who were also admitted at much younger ages (approximately 25 years younger than adults without IDD). These studies provided important and new information about the health and health care needs of adults with IDD in Ontario.

These findings were shared with approximately 200 family members, researchers, service providers, and decision-makers from both the developmental services and health sectors across Ontario during a knowledge transfer webinar. The vast majority of participants viewed the health and developmental services sectors as not being ready to handle the needs of an aging population with IDD – and cited insufficient cross-sector expertise and inadequate funding among the main reasons for this. The group also noted that complex health care needs, challenged informal supports, and lack of services contributed to use of both home care and long-term care services in this population. Continued access to quality, population-level data is needed to improve the ability of health and developmental services sectors to respond to needs, and improve practices and policies to support adults with IDD to age in the community.

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UPCOMING EVENT

5th IASSIDD
Europe Congress

Diversity & Belonging:
Celebrating Difference

Wednesday 18 July – Friday 20 July 2018

Tuesday 17 July 2018: IASSIDD Academy pre-conference workshops

Saturday 21 July 2018: Post-conference day for parents, persons with disabilities & practitioners

Venue: Divani Caravel hotel, Athens
Local convenors: Association of Parents Guardians and Friends for Persons with Autism Larissa, Greece
More information: www.iassidd.org

Save the Dates – Mark your Calendars – Save the Dates – Mark your Calendars