SUMMARY REPORT

The SAge-ID Study: The Predictors and Correlates of Cognitive Decline in People with Intellectual Disability: a Questionnaire study

Dementia Collaborative Research Centre
Assessment and Better Care

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The SAge-ID Study: The Predictors and Correlates of Cognitive Decline in People with Intellectual Disability: a Questionnaire study

Australia’s population is rapidly ageing and Australians with intellectual disability are now living well into late life. Despite this, there is a lack of information pertaining to the health needs of ageing people with intellectual disability, as well as their carers. Unmet health needs of ageing people with intellectual disability, along with demands on their carers, are expected to further increase over the next 20 – 30 years. The Successful Ageing in Intellectual Disability (SAge-ID) study investigated the prevalence of dementia in people with intellectual disability, as well as health and lifestyle factors that may be associated with developing dementia. The study also investigated factors that may affect the health and wellbeing of carers and the level of unmet mental health needs and barriers to services that exist for ageing people with intellectual disability.

Participants in the study included older adults (aged 40 and over, average age 51 years) with intellectual disability, and their family carers, recruited from metropolitan and rural regions of New South Wales and Victoria. Questionnaires and interviews were used to find out about the person with intellectual disability’s physical and mental health, adaptive behaviours, lifestyle and any changes or declines in thinking or memory. Neuropsychological tests were also undertaken to aid assessment of the person with intellectual disability’s cognitive status at clinical case consensus. Family carers also completed questionnaires about their own mental health and wellbeing. Focus groups were also held with selected family carers of people with intellectual disability, in order to explore carers’ experiences of caring and of accessing mental health services for the person with intellectual disability.

Most people with intellectual disability in the study were single and lived in small residential care facilities, with some living with family carers and a smaller number living independently. People tended to have a lower level of adaptive functioning, which suggests a more severely affected cohort compared with the broader population with intellectual disability. Mental health problems were common, with a previously diagnosed mental health problem reported in over one third of people with intellectual disability in the study, with people who have a higher level of adaptive functioning more likely to have previously received a diagnosis of a mental health problem. People with a previous formally diagnosed mental health problem also had higher levels of problem behaviour, experienced more stressful life events and took more medication compared with those who had no prior mental health diagnosis.

People with Down syndrome had significantly higher rates of dementia, compared with people of similar age from the general population. Some people with intellectual disability from causes other than Down syndrome also had dementia. However, because the numbers were small, it was difficult to validly compare the rates of dementia in those without Down syndrome against the general population. We will continue to follow people in the study overtime and this will provide a clearer picture of the prevalence and course of dementia in people with intellectual disability. Many people also had one or more chronic illnesses, with a chronic illness present in half of people with intellectual disability and multimorbidity (two or more illnesses occurring together) of physical health conditions was highly prevalent in this group, especially as people got older. Other types of disabilities occurring alongside the
intellectual disability were also common. Almost three quarters of the people in the present study were overweight, which is higher than in the Australian population. Almost half of people with intellectual disability experienced sleep problems. Despite high rates of mental health problems, a substantial proportion of people were not accessing appropriate health services, with almost 40% of people with a diagnosed mental health problem not accessing a mental health professional within a 12 month period, and almost half of people taking a psychiatric medication not accessing a mental health professional within a 12 month period.

Family carers of people with intellectual disability were, on average, in their late 60’s and the carer was most often the mother of the person with intellectual disability, with a substantial minority being a sibling. Half of carers were married and were no longer working. Depression was present in a substantial proportion of family carers and the level of psychological distress was higher than expected, compared with the general population. Female carers were more likely to experience depression. Overall, depression was associated with financial hardship, not being able to do all the things that they would like to do and a prior diagnosis of a mental health problem in their relative with intellectual disability. Psychological distress was present more often in younger carers, and was also associated with difficulty getting around, not being able to do all the things that they would like to do, and having to also care for other people.

Carers who participated in focus groups described a mix of positive and negative experiences relating to their caring role. Some described their caring role as a ‘lifetime job’ that meant sacrificing their own needs and giving up alternative life plans. Another common theme was the experience of stigma and discrimination from both family members and the community which resulted in a high level of emotional, psychological and physical stress. Carers also reported anxiety as to what would happen to the person with intellectual disability that they cared for when they themselves were no longer able to provide care. However, whilst caring for the person with intellectual disability did sometimes result in barriers between themselves and other family members, carers also reported the positive effects of forming close bonds between family members and bringing the family together.

Taken together, the results of the study suggest that improved access to health services including preventative health programs for people with intellectual disability is needed. Achieving this will require the upskilling of health professionals and equipping the service sector so that it is able to make reasonable adjustments and coordinate seamlessly across multiple agencies. There is a need to equip aged care and disability sectors to better meet the needs of people with intellectual disability as they age, particularly screening for symptoms of dementia in people over the age of 40. Development of targeted interventions and flexible support networks, including psychotherapeutic interventions, that aim to alleviate carer depression and distress and increase coping skills are necessary to improve carer wellbeing. Health professionals for ageing adults with intellectual disability are uniquely placed to provide support and information to carers.

Improved interagency coordination, especially for those with multiple and complex disabilities, is required and should be promoted as part of the incoming National Disability Insurance Scheme (NDIS). An essential element of this is planning
transition of care arrangements and ensuring access to appropriate mental health services. Attention to these factors will likely improve carers’ wellbeing as well as that of the person with intellectual disability. Addressing the mental health needs of ageing carers is also needed and makes fiscal sense given the immense cost benefit that is achieved when family carers can continue to care. Whether via the NDIS, or through the expansion of other funding mechanisms, programs and information services for this unique group of carers should be promoted.

The SAge-ID study is continuing to follow-up participants throughout 2015.