Symposium: Aging in Ireland

Physical health and multiple morbidity in Irish people with an intellectual disability as they age
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Aim: There are concerns in Ireland that for ageing people with intellectual disability (ID), mortality is higher and health problems are greater than for the general population. The Irish Longitudinal Study of Ageing (TILDA) has been extended with an intellectual disability supplement (IDS-TILDA) to investigate these concerns. This paper aims to profile multiple physical health morbidity in people with an ID as they age in Ireland. Method: A representative sample of 753 persons aged 40 plus with ID drawn randomly from the National ID database (NIDD) have responded (or carers have responded on their behalf) to questionnaires addressing demographics, health, health utilization, medication usage, and ADL/IADLs. The relationship between multiple morbidity, age, and level of ID was investigated. Results: The ageing of people with ID has been similar in many respects to that of the general population but there are important differences in physical health, incidence of dementia, epilepsy, diabetes, heart disease and cancers. Multiple morbidity appeared associated with age, level of ID and poor self-rating of rate health. Conclusions: Awareness of multiple morbidity is an important consideration in the development of health services for people with ID as they age.

An exploration of the resilience of ageing family caregivers of older people with intellectual disabilities living at home
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Aim: As the majority of older adults with an intellectual disability (ID) remaining living in the family home, this imposes challenges on family carers, who are also ageing and have support needs of their own, and on service provision. This study explored the resilience of ageing family carers caring for an older person with an ID living at home. Method: A qualitative approach was employed. Eighteen one-to-one interviews were undertaken with ageing carers. The qualitative data was analysed using thematic content analysis. Results: Findings revealed carers' physical and mental health and the supports available to them in relation to the continuity of their relatives care within the home. Caring had positive and negative health and social outcomes for older carers, namely satisfactions and rewards, stress, diminished physical health and social networks. Conclusions: Services will need to evolve focusing on providing information on future planning, offering education and training, as well as emotional and instrumental support to families in order to build upon their existing strengths and to empower family carers within their own social context as a form of prevention, maintenance and also crisis management.

Growing older with intellectual disability
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Aim: People with intellectual disabilities are not only living longer but most now age within community-based services. In times of austerity, the identification of priorities is crucial. Method: Around 40 delegates from a range of disciplines and organisations on the island of Ireland were invited to round table discussions to analyse the implications for future policy and practice of data emerging from ongoing research studies (McCarron et al, 2011; Taggart et al, 2011). A striking consensus emerged as to five main priority areas and within each, two ‘low-cost’ actions were identified. Results: Promoting health and wellbeing as people age was a major priority with actions focussed on health screening and individual planning. New styles of services were required, notably in day opportunities and through individualised payments. Greater integration with mainstream older persons services was advocated, especially in supported accommodation and for specialised services such as with dementia. Augmented family support services will be required including short breaks and facilitating succession planning within families. Policy imperatives were around improved training and local area planning. Conclusions: These proposals provide an agenda for future research and evaluation studies, including the cost-effectiveness of realising the proposed actions.

Symposium: Researching end of life

Experiences of community living staff assisting people with intellectual disability to know about dying as the end of life approaches
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Aim: The aim of this study was to explore community living staff experiences of engaging people with intellectual disability to know about dying and death. Method: Guided by grounded theory methodology, focus groups and individual interviews were conducted with a range of staff, including those who had not yet experienced a client death, those who had experienced sudden client deaths, and those who had experienced client deaths pre-dated by extensive end-of-life care. Results: The presentation will report on both the staff ‘in-principle’ beliefs and ‘in-practice’ engagement with clients to know about dying and death. The influence of staff experience, client capacity to understand, and the opportunities for engagement will be discussed. These results will be presented against a landscape demonstrating that people with intellectual disability have been, and will continue to be, exposed to death. Conclusions: People with intellectual disability have a right to know about dying and death. Recommendations will be made about how we can ensure that community living staff are well equipped to assist people with intellectual disability to exercise this right.

Disenfranchised grief: A parent with an intellectual disability shares her story
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Aim: The death of a child is, for many people, often perceived as the ultimate loss. For a young woman with an intellectual disability, coming to terms with the death of her son following a termination was a difficult process, as she was never encouraged nor helped to mourn her death. Twelve years following her death she asked to speak with a bereavement counsellor. Method: This single case study introduces the lived experience of the bereaved parent, explores the challenges encountered along the way, and describes the healing process in which the bereaved parent came to terms with her loss. Results: Mourning rituals can help the bereaved to accommodate loss, and sometimes people with an ID need specific help and support with this. In this case, it was 12 years after her son had died that the parent was sensitively supported to constructively explore the impact and meaning of the loss of her son. Conclusions: Telling, writing and sharing stories can be cathartic, and in this paper a woman proudly shares her story and experiences of loss in the hope that others can learn from it. Life story work played a key role in supporting this person’s grief work.

Defining premature death in people with intellectual disabilities
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Aim: A Confidential Inquiry (CI) into the deaths of people with learning difficulties in the U.K. aims to improve the health and wellbeing of people with intellectual disabilities. Method: Following the notification of the death of a person with intellectual disabilities who meets the CI criteria, a full investigation is undertaken adopting a root cause analysis methodology. All cases are then reviewed independently by a multi-disciplinary Overview Panel. Results: There are a number of ways in which what constitutes a ‘premature death’ might be determined. A central aspect of the CI work has been to establish which is the most appropriate and robust way of defining premature death in this context. The approach taken is to consider the sequence of events leading to death. Therefore a death is considered premature if, without a specific event that formed part of the ‘pathway’ that led to death, it was probable (i.e. more likely than not) that the person would have continued to live for at least 1 more year. Conclusions: This paper will briefly review the different ways to determine if a death is premature and will present a few vignettes to illustrate the method selected by the CI Team.