Symposium: End of life care
Understanding end of life care for people with intellectual and developmental disabilities

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Aim: In the United States, people with intellectual or developmental disabilities (IDD) experience worse health and more barriers to quality health care, despite having a life-expectancy equivalent to that of the general population. This disparity is particularly salient at the end of life. The aim of this study is to describe the experiences of people with IDD, and their professional and family caregivers on end-of-life care. This study is unique because end-of-life care data are obtained directly from people with IDD. Method: A qualitative, exploratory approach was used to collect focus group and individual interview data from people with IDD, and family and professional caregivers. Family and staff participants experienced the death of an adult with IDD, and participants with IDD experienced the loss of someone close to them. Results: Participants vividly recalled losing a loved one and their experiences surrounding the loss. Family and staff participants described the facilitators and barriers to quality end-of-life care. All of the participant groups discussed improving end-of-life care for people with IDD. Conclusions: Findings from this study provide a foundation for understanding how end-of-life care is currently being administered, identifies the gaps in our current understanding, and outlines areas that need improvement.

Issues raised by community living staff caring for people with intellectual disability approaching the end-of-life

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Aim: The aim of this study was to explore the current status of end-of-life care and dying of people with intellectual disability as experienced by staff of community living services in Australia. Method: A qualitative, exploratory approach was used to collect focus group and individual interviews were conducted with staff, guided by grounded theory methodology. Results: The presentation reports on five identified key issues: knowledge of dying, ethical values, the where of the caring, the how of the caring, and post-death caring. The presentation also details how these issues occurred in relationship to the participants involved, including the dying person, fellow clients, family, external health services and the coroner. Conclusions: End-of-life care represents a complex interaction between the care issues and the partners involved in care. A sophisticated staff skill set is required to ensure that community living services can offer people with intellectual disability quality care at the end of their life.

Communicating with children and young people: A Toolkit to support end of life care

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Aim: A toolkit can be described as a set of tools designed for a specific type of work, kept in a special box or bag, or a collection of information, resources or advice for a specific area or activity. This paper introduces a toolkit, funded by the UK Department of Health, entitled Communicating with Children, Young People and Families Where There is a Learning Disability, to help professional carers when providing end-of-life care. This presentation provides the rationale for the project, describes how the toolkit was developed, introduces the toolkit itself, and explores its potential from an educational and practical perspective. Method: Action research provided a framework for development of the toolkit and involved a range of practitioners. Results: Collaborative approaches to the toolkit development enabled the resource to be flexible and practical. The toolkit has 26 components to help palliative care professionals in a variety of healthcare settings and contexts. Conclusions: Toolkits need to be accessible, portable, flexible and cost effective to reach their maximum potential. They also have to fit the purpose of use. Action research provided an appropriate framework to enable a range of practitioners to work together to ensure the resource was a fit with purpose.

Symposium: Multiple topics: Services and dementia
Ageing with an intellectual disability in rural areas

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Aim: In recent years, a combination of factors have seen life expectancies for people with intellectual disabilities increase dramatically. While this improvement is naturally a very desirable outcome, there are limited policy frameworks and little information regarding the impact of rurality on this relatively new phenomenon. The purpose of this study was to gain an understanding from Australian disability-support staff in rural areas regarding the most important issues facing them as they support people with IDD. Method: A three-round Delphi research model was utilised over a period of twelve months. The participant group (N = 31) included representatives from fourteen different rural-based disability service agencies. Results and Conclusions: A thematic analysis identified specific areas of concern including funding, inadequate/inappropriate training, access to relevant services, medical/health problems, time constraints, and family dynamics. The results detail a number of important items relating to the ageing of people with intellectual disabilities in rural localities. The findings have implications for Government Departments, disability service providers, and training entities, in both the delivery of services to individuals with intellectual disabilities who are ageing and the training of the staff who support this cohort of people.

Towards developing an understanding of individual experiences of ID and dementia

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Aim: To begin to understand how people with intellectual disabilities (ID) construct their experiences of dementia. Method: A longitudinal, ethnographic approach to this PhD study produced three individual case reports. Fieldnotes, pictorial documentation, narrative, and nonverbal communication supported observations of the lives of participants living in an ID group home, a generic care home for older people, and alone with outreach support. Results: The experiences of people with ID were not constructed by dementia, as this diagnosis was not shared with them. Nor were experiences constructed by their care setting but by the practices within that setting. People with ID and dementia became marginalised due to a significant lack of crossover of knowledge between staff working in ID settings and in dementia settings. This happened even if the participant had previously enjoyed a socially active, independent lifestyle. Conclusions: Not sharing the diagnosis of dementia, or information relating to the diagnosis, was the starting point for the emerging pattern of stigma and increased isolation. The research highlights how the inclusion of people with ID and dementia in research and practice has not progressed at the same rate as it has separately for people with ID and people with dementia.

Using Balanced Scorecard to maintain consumer-driven outcomes in organisation-wide change for older adults with intellectual disability

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Aim: A 4-year project of organizational change is underway by New Zealand's largest disability provider to strengthen its ability to support people who are ageing. Method: The scale of the project necessitated robust project management and evaluation to ensure initiatives achieved goals, organizational change occurred, and all stakeholders engaged. A Balanced Scorecard process was adopted to implement a plan with measurable consumer-driven performance indicators. Results: IHC can track progress toward consumer objectives, while simultaneously developing internal procedures. Conclusions: This presentation will describe what pre-existing research has guided the project planning process, and the impact that this has had on the project's outcomes.