Conference Abstract

Key issues and research priorities affecting social outcomes for an older population: differentiating adulthood, hearing and acting on the perspectives of older people with intellectual disability

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Abstract

At the broadest level, international covenants and domestic social policies in most developed countries regard people with intellectual disability as citizens with equal rights. By implication, these policies suggest that they should expect the same opportunities and support for an active old age as the general community. However, the increased life expectancy of people with intellectual disability has too often been associated with anxiety that older parents hold about the future when they will no longer be there to act as both carers and advocates, and concerns of service providers and policy makers about responding to the changed or additional support needs of aging clients. In comparison little recognition has been given to the potential opportunities that middle and later life might hold for people with intellectual disability or their own perspectives on this period of the life course. The emphasis on future planning may have overshadowed a focus on the present, as plans sometimes focus on a fixed, static future characterized by security rather than the continuing developmental potential of adults to learn new skills, or acquire new interests and relationships in middle age and beyond.

This presentation draws on a series of Australian studies about aging and people with intellectual disability to explore differing perceptions of growing older with a disability, examine the life circumstances of older people and the type of support that has been available to them. These studies show that: people with intellectual disability hold purposeful ideas about the future but also see retirement as being inherently risky; they are dependent on disability day services as a base for activity and social relationships, yet connections to such services are fragile; others exercise significant power and control over their lives and decisions made can fragment their lives, be driven by narrow or restricted visions about possibilities or resource constraints.
Service providers often fail to translate the principles and strategies that inform work with younger people with disabilities to their work with older people. As they age people with intellectual disability are at risk of being moved to larger congregate and more restrictive living environments and having such small social networks that they are known well by few people.

The picture emerges of a significant gap between the aspirations and experiences of people aging with intellectual disability and a disconnection between the expectations of staff and people themselves about later life. People with intellectual disability have a weak voice in shaping their own lives with few allies to draw out their own perspectives. Middle as a distinctive phase of life has been masked and its associated challenges of renegotiating family relationships, constructing meaning from one's life and finding ways of contributing to the community remain unexplored in respect of people with intellectual disability.

This gloomy picture raises significant challenges for social researchers; to find research approaches that give a greater voice to people with intellectual disability and their own views about aging; to uncover the mechanisms that lead to the formation of robust social networks that include strong and resourceful allies; to forge a differentiation of adult life that mirrors that of the general community and begin to explore middle as well as old age for people with intellectual disability; and to examine how the way of working with younger adults, for example to find and support employment, may be adapted to negotiating and facilitating inclusion of older people in meaningful or organised community participation endeavors such as volunteering, or group membership.

Keywords

older adults, intellectual disabilities, public policy, social care, aging

Presentation available from the FICCDAT Growing Older conference site