CAREGIVING CAPACITY AND FUTURE CARE PLANNING OF FAMILY CARERS FOR OLDER PEOPLE WITH AN INTELLECTUAL DISABILITY IN IRELAND

Damien Brennan1, Rebecca Murphy1, Philip McCallion2, Mary McCarron1
1Trinity College Dublin, Dublin, Ireland
2University at Albany, State University of New York, USA

Background: Within contemporary Irish society, families within their homes are the primary providers of caregiving support for people with an ID. However, as people with an ID age so too do their families, making family caregiving more difficult and complex. This study examined the caregiving capacity and future care plans of parent and sibling carers for their ageing family member with an ID.

Methods: Situated with the parent study population of IDS TILDA (Intellectual Disability Supplement to The Irish Longitudinal Database on Ageing), a qualitative study design was employed with a purposive sample of parent and sibling carers (n = 17) of older people with an ID. Five focus groups and six semi-structured interviews were conducted and analysed.

Results: Family caregiving capacity was compromised by limitations and anomalies in contemporary carer support systems, particularly the reduced and varied availability of carer’s allowance, day care and respite care.

Few carers have definitively formulated future care plans with their family member with an ID or the wider familial network, and where plans do exist these are predominantly aspirational in nature.

Sibling caregivers in particular felt physically, psychologically, and intellectually restricted and unsupported in their primary carer role. Furthermore, the majority of families articulated that they represented the last remnant of family caregiving capacity existing within the family.

Families anticipated future crisis management and foresaw a strong possibility of their family member with an ID requiring residential out-of-family home care provision at some point in the future.

Conclusion: Carers allowance, day services and respite care are key to improving the quality and sustainability of family caregiving for older people with an ID.

Families’ future care planning and the future need for tailored residential service provision for the older cohort of people with an ID necessitates clarification, costing and policy planning.