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Decision-making regarding transitions to residential care for people with intellectual disabilities

Dr Caroline Egan; Dr Geri McLoughlin; Prof Corina Naughton; Prof Ruth Northway and Dr Helen Mulcahy

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Decision-making regarding transitions to residential care for people with intellectual disabilities

Caroline Egan, School of Nursing and Midwifery, University College Cork
caroline.egan@ucc.ie

Executive Summary

People with intellectual disabilities are living longer often with ageing family caregivers [1,2,3] As needs increase and community services remain limited, families face pressure that can lead to emergency residential placements. This PhD study examines the experiences of people with intellectual disabilities and their family caregivers as they seek residential care in Ireland [4,5,6,7].

Families reported they avoided future planning because it was emotionally difficult. Decisions were usually crisis-driven, with varied involvement of the person with intellectual disabilities. Limited statutory support and complex family dynamics, shaped decision-making and planning for residential care, often working against the goal of *ageing in place* and resulting in unplanned, emergency transitions to residential services.

Policy recommendations centre on the development and evaluation of a person-centred model of care for ageing with an intellectual disability. This model should support *ageing in place* wherever possible and enable planned, and well-coordinated transitions to residential care when or if they became necessary. Such an approach is essential for building a coordinated, transparent, and rights-based system of care.

Finally, there is a need to strengthen research partnerships, expand co-design and Patient and Public Involvement, co-produce a transitional care model, and pilot it with dedicated funding.

Key Insights

- Ageing and increasing care needs place families under pressure, often leading to difficult decisions about future care.

UCD Geary Institute for Public Policy, University College Dublin, Belfield, Dublin 4, Ireland.
Phone: +353 1 716 4615 Website: https://www.ucd.ie/geary Email: geary@ucd.ie

- Crisis-driven admissions to residential care are increasingly common due to a lack of community support [2].
- Emergency placements can limit the person's voice and choice, raising human rights concerns [8, 9].
- There is limited national data to guide policy and service planning.
- Policy recommendations centre on the development and evaluation of a person-centred model of care

Research Overview

People with intellectual disabilities often experience residential transitions in mid to later life. These transitions are shaped by ageing-related challenges, caregiver capacity, and wider factors such as policy and service availability.

Population ageing within the intellectual disability community is creating increasing demands on disability and health services in Ireland. Census 2022 identified 109,288 people with an intellectual disability, with notable growth in the 40 to 59-year age groups [10] The Department of Health's *Disability Capacity Review to 2032* highlighted concerns regarding the capacity of existing services to meet future need and identified a risk of emergency placements resulting from crises in family caregiving or service provision[2]. Reflecting this growing demand, the HRB reported that over 2,000 adults required a residential placement, the majority of whom had an intellectual disability, were ageing, and were supported by ageing family carers[3]. These trends underscore the importance of better understanding and supporting residential transitions among ageing adults with intellectual disabilities.

Residential transitions can be particularly challenging and are frequently associated with a loss of autonomy and control. The UNCRPD[7] recognises the right of people with disabilities to live independently and make choices about where and with whom they live. In Ireland, the Assisted Decision-Making (Capacity) Act[8], reinforces these rights through a presumption of capacity and a focus on an individual's will and preferences. These commitments highlight the importance of involving people with intellectual disabilities in decisions about future living arrangements. However, service and resource constraints limit opportunities for meaningful participation in decision-making[2, 11].

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This PhD project[4] explored how people with intellectual disabilities and their families plan and decide about permanent moves from home into residential care. Two literature reviews[5,6] highlighted the lack of attention directed to their lived experience during future planning and residential transitions. Twelve participants (six adults with intellectual disabilities and six family caregivers) who had applied for full-time residential care were interviewed. A research approach called interpretive phenomenological analysis was used. People with intellectual disabilities were involved in the design to ensure inclusion and ethical approval.

Research findings

—Families said things were changing rapidly at home, which meant hard decisions had to be faced that some people did not like.

—Many families avoided planning for the future because it was upsetting and uncertain.

—Caregivers involved the person with intellectual disabilities in planning based on what they thought they could cope with and wanted to be involved in.

—Decisions were usually made out of necessity rather than through planning ahead.

—Family relationships and constrained statutory services strongly affected this period and how decisions were made.

—The findings highlight a lack of policy and service provisions necessary to support families through these periods of change.

Policy Implications

— Create evidence-based guidelines to support residential transitions

In the short term, health and social care services need to be adequately resourced and supported with practical, research-informed policies and tools that help families and health and social care staff manage care transitions equitably and consistently.

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— **Develop a person-centred relocation model**

Reflecting human rights and legal obligations, policies must ensure that any relocation or change in care is guided by the individual's and family's needs, preferences, and wellbeing—not by service pressures.

— **Invest in services so people can age in place.**

Policy should focus on enabling people with intellectual disabilities to stay in their own homes and communities as they age, supported by flexible and integrated community-based services.

— **Shift from crisis-driven responses to planned support.**

Ensure adequate funding and capacity so that families and services can plan ahead with people rather than react to emergencies.

— **Build a coordinated, transparent system across families, community, and government levels.**

Establish a clear, joined-up service model for ageing with an intellectual disability, grounded in a disability philosophy of care and supported by sustainable funding and transparency about service gaps at all levels.

Recommended Actions

- Build partnerships and collaborations with people with disabilities and their families, alongside key stakeholders including politicians, researchers and organisations working in ageing and intellectual disability, to strengthen the policy evidence base.
- Engage in co-design and Public and Patient Involvement (PPI) with people with intellectual disabilities, families, service providers, and policymakers to identify priorities and ensure grounded, inclusive development.
- Co-produce a draft model of transitional care including pathways to age in place, home-based supports, proactive transition planning, and resource requirements.

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- Secure funding to pilot the model across several representative services and geographical areas to assess feasibility, costs, and improvements prior to wider rollout.

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