

Planning for the future among older parents of adults with intellectual disability



Image source: <https://www.unitingcommunities.org/disability-services/home-based-care-homelink/>

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Background



- People with intellectual disability (ID) are living longer.
- Extended caregiving role for parents.
- Adults with ID have a right to choose where and how they live.
- Most older parents do not have plans for the future.

Research projects

- Caregiving dynamics and futures planning among ageing parents of adults with intellectual disability. 2015-2016
- The experiences of ageing carers of adults with intellectual disability from Greek and Italian migrant backgrounds living in Australia. 2017-2018
- The support and service needs of older carers of adults with intellectual disability - 2019-2020
- Choosing the way forward: Post-parental housing transitions among adults with intellectual disability - ARC Linkage project. 2021-2024

Study 1 - Caregiving dynamics and futures planning among ageing parents of adults with intellectual disability

- The number of older parents ageing in tandem with their adult children with ID is increasing.
- Need for research that investigates how older parents experience this extended caregiving role, including the extent to which they are engaging in futures planning.
- Most research has focused on those living in family home.
- Participants were recruited via disability service providers in South Australia. In-depth semi-structured interviews were carried out with older parents (N = 17, mean age 70 years). Six adults with ID were living in the family home while the remainder were living in supported disability accommodation.

- Main themes : (a) perpetual parenting, (b) costs and rewards and (c) planning to plan.
- Parents were providing care across a range of areas, regardless of whether their son/daughter lived at home or in supported accommodation.
- While parents acknowledged 'costs' associated with the role, it also gave them a sense of purpose and pride as well as benefiting from reciprocal care.
- While aware of the need to plan for the future, most did not have a firm plan in place.



Study 2 - The experiences of ageing carers of adults with intellectual disability from Greek and Italian migrant backgrounds living in Australia

- Little is known about how older parent caregivers from culturally and linguistically diverse backgrounds (CALD) experience caring for their family member with ID into late life.
- Determine whether future plans for care and accommodation exist and what these are.
- Two of the largest cohorts of older post-war migrants are those born in Italy & Greece.

Walker R, Hutchinson C, Gordon S, Belperio I, Rillotta F. (2020). 'Caring for a family member with intellectual disability into old age: applying the sociocultural stress and coping model to Italian and Greek migrants in Australia'. *Journal of Applied Research in Intellectual Disabilities*. 33(5), 887-897. DOI:10.1111/jar.12710.

- Recruitment via disability service providers, culturally-specific community services, personal contacts.
- Greek and Italian research assistants; interviews conducted in preferred language as required.
- In-depth semi-structured interviews with n=19 carers aged 50-91 from 4 Greek families and 10 Italian families, predominantly mothers and siblings.

Walker R, Hutchinson C, Gordon S, Belperio I, Rillotta F. (2020). 'Caring for a family member with intellectual disability into old age: applying the sociocultural stress and coping model to Italian and Greek migrants in Australia'. *Journal of Applied Research in Intellectual Disabilities*. 33(5), 887-897. DOI:10.1111/jar.12710.

- Main themes : (a) it's our responsibility, (b) uncertain futures and (c) the paradox of filial responsibility.
- Providing on-going care for their family member with ID as they age is highly valued among older parents from Greek and Italian backgrounds.
- Parents upset thinking about the future; thinks about future all the time but avoiding making firm plans.
- The (cultural?) expectation that family members, such as siblings, will assume the primary caregiver role in the future is shifting, creating potential vulnerability for their family member with ID.

Walker R, Hutchinson C, Gordon S, Belperio I, Rillotta F. (2020). 'Caring for a family member with intellectual disability into old age: applying the sociocultural stress and coping model to Italian and Greek migrants in Australia'. *Journal of Applied Research in Intellectual Disabilities*. 33(5), 887-897. DOI:10.1111/jar.12710.

So, where to from here?



Study 3 - The support and service needs of older carers of adults with intellectual disability

- How can we support older parents to put plans in place for the future.
- Range of interventions developed internationally which have sought to assist family carers to plan for the future - only loosely informed by older carers themselves.

Supported by Office for Ageing Well



Government of South Australia
SA Health



Study 3 - The support and service needs of older carers of adults with intellectual disability

- 3 focus groups; 28 participants recruited via key stakeholders in the disability and ageing sectors, Office for Ageing Well SA Health, Department of Human Services and metropolitan councils.
- Key question: *What assistance, resources or programs could support older carers to plan for the future care of their family member with intellectual disability?*

Walker R, Belperio I, Rillotta F & Sage-Jacobson S. (2020). *The support and service needs of older carers of adults with intellectual disability*. Report to the South Australian Office for Ageing Well.

Accommodation

*“Well, **where they live is the big one.** It’s the elephant in the room.”*

*“I find it a catch 22 because they’re saying don’t leave it until it’s a crisis because that means that there are not nearly as many things in place to find the **appropriate accommodation** for your child ... The issue with that though, is **when is the right time?**”*

- No single solution to assist with future planning, but a range of areas in which older carers need support to give them the ability (or 'headspace') to plan.
- These included:
 - Having clarity about out-of-home accommodation options
 - Someone to take person-centred, holistic care of their family member
 - Having access to relevant information tailored to their needs as carers; including legal and financial advice
 - Having their physical and emotional needs recognised

ARC Linkage project

- Choosing the way forward: addressing post-parental housing transition needs of adults with intellectual disability and their older carers
- 2021-2024
- 3 Stages

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Australian Government
Australian Research Council



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Industry partners

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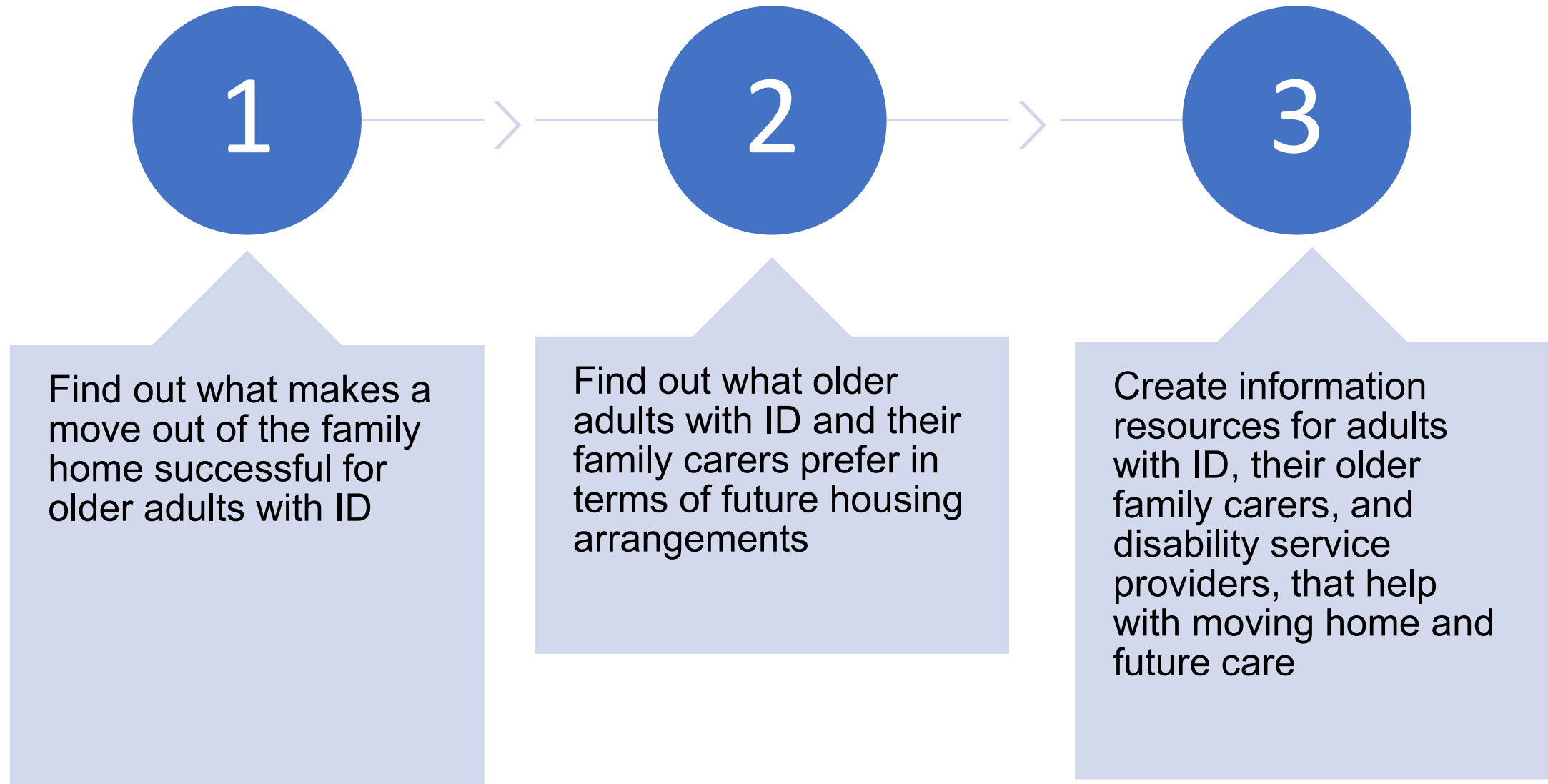




Aims

- To address the urgent issue of growing numbers of older people with intellectual disabilities outliving their parent carers who have not put future care plans in place.
- To generate a national evidence-based framework for ensuring successful post-parental housing and care transitions.

Objectives and stages



Stage 1

- *Interviews in Adelaide, Sydney and Melbourne with:*
 - a) Adults with ID who have moved out of the family home in the past 2 years
 - b) Their parents or other carers who have helped with this move (approx. 10 dyads/pairs in each city)
 - c) Disability service providers who have helped adults with ID and their families to move out of the family home in the past 2 years (30 interviews)

Stage 2

Part 1. Interviews in Adelaide, Sydney and Melbourne with:

- a) Adults with ID living with older parents who are planning to, or thinking about, moving out of the family home
- b) Their parents or other carers who are helping them with this (approx. 10 dyads/pairs in each city)

Part 2. Follow-up survey with:

- a) Adults with ID living with older parents where the family has thought about future housing and care (200 families)



Stage 3

Part 1. 2 workshops where information resources are co-designed with:

- a) Adults with ID
- b) Families or other carers of adults with ID
- c) Project Advisory Group

Part 2. The information resources created in Part 1 will be checked by:

- a) Adults with ID
- b) Families and other carers of adults with ID
(45 participants from Adelaide, Sydney and Melbourne)

PhD scholarship opportunity!

Interested in doing a PhD or know someone who is?

We have a 3 year fully-funded PhD scholarship working on our ARC Linkage project exploring the experiences of adults with intellectual disability transitioning from the family home to alternative living arrangements

Contact me if you are interested:

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