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# Post-parental care planning in rural (South) Australia

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*I guess (the most important thing) would probably be who would be able to provide the care for her and where would she go ... I'm worried about what's going to happen to her because she doesn't have a voice.*

***[Mother]***

*I have to learn to trust that someone will be able to take over that role ... it's just getting that trust and working out the best option for him going into that care.*

***[Father]***

# Why did we do this study?

There has been little research on how rural communities support people with intellectual disability and their older parental carers.

We received an Australian Research Council Grant to look at how rural families and disability service workers can work together to support people with intellectual disability to move out of their family home when their parents may be no longer able to support them.

# Where did we do this study?

We decided to talk with people in rural areas of South Australia. This was due to the fact that not much research had previously been done in rural South Australia.

We had a partner organisation called Uniting Communities. They helped us to talk with people in a range of places in rural South Australia including:

- ▶ Tanunda,
- ▶ Port Augusta,
- ▶ Murray Bridge,
- ▶ Kadina, and
- ▶ Port Lincoln.

# What did we do?

We talked with different people about how individuals are helped to move out of home.

There were four different groups we spoke to:

- ▶ **Focus Groups with 9 Disability Service Workers**
- ▶ **Individual Interviews with 11 older carers (three mothers, one father, two couples, two sisters and one brother)**
- ▶ **Individual interviews with 5 individuals with Intellectual Disability**
- ▶ **Co-Design Interviews with 4 carers and 3 disability support coordinators**

# How we looked at our data

- ▶ All interviews were recorded and then written out ‘word for word’.
- ▶ We used a process called “thematic analysis” to examine what everyone said in the interviews.
- ▶ We used guidelines by two researchers called Virginia Braun and Victoria Clarke to help us do our thematic analysis.
- ▶ This allowed us to identify the key ideas that the people told us.

# What did we find out?

- ▶ There is general lack of support to assist people with planning in rural South Australia
- ▶ There is a lack of appropriate housing services for these individuals in particular
- ▶ There is a current shortage of appropriate staff across all human and social services
- ▶ Governments are not helping people to find qualified and knowledgeable rural staff
- ▶ Keeping staff with experience and knowledge is difficult

# What did we find out?

- ▶ It takes far too long to support people to move into the community. This means that their parents get very tired and cannot continue to provide support.
- ▶ There are often no choice in service options for people with intellectual disability when they want to move out.
- ▶ There is a lack of understanding of the goals of adults with intellectual disabilities.
- ▶ Rural staff often work by themselves with limited support from local managers.

# What should we do next?

**Recommendation 1:** We need to focus on what the person with intellectual disability wants and values in order to increase their quality of life after moving into the community.

**Recommendation 2:** We should work together to advertising nationally to attract staff into the disability sector. This advertising should tell everyone how staff are developing higher level skillsets.

**Recommendation 3:** Government should offer incentive payments to attract staff to rural disability providers. Government already does this with other workplaces through programs like the Regional Jobs Support and Incentive Program.

# What should we do next?

**Recommendation 4:** We should support staff to work together. This will allow staff who have experience in supporting individuals and their families with post-parental care planning across rural areas to assist staff who do not have this experience.

**Recommendation 5:** We need to develop transition resources for persons with intellectual disability and their families with a focus on choice and decision making.

# What should we do next?

**Recommendation 6:** We need to make sure that support is available well before the need for transition becomes urgent.

**Recommendation 7:** We should use technology to assist people but it should be informed by the individuals that will use it.

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The views expressed are those of the authors and are not necessarily those of the Australian Research Council or the partner organisation.



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