

# Barriers and impediments to providing end-of-life care in rural Australia

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# Background

- ▶ Life expectancy for persons with intellectual disability has increased dramatically over the past decade, which has seen an associated rise in the need for end-of-life care (across all age brackets).
- ▶ However, limited knowledge is available regarding the barriers to accessing necessary end-of- life care support, particularly in rural locations in Australia.

# Reports and Reforms



*However, there remain substantial gaps between philosophy and articulation of these reports into practical, achievable outcomes. Neither report successfully addressed the issue of end-of-life care for people with intellectual disability.*

# Identified Issues

- ▶ Very limited end-of-life care support services for people with intellectual disabilities in rural areas
- ▶ Difficulty in accessing and/or transitioning people between services effectively.
- ▶ Problems for services and families in managing:
  - ▶ Quality of life
  - ▶ Medications and its side effects
  - ▶ Dementia
  - ▶ Early identification of emerging health issues

# The Current Research Project

## Aims

- ▶ Explore key dimensions that enable or impede the provision of appropriate community-based *end-of-life care* options for people with intellectual disabilities in rural areas
- ▶ To develop a better understanding of the complex range of issues and the interplay of health, social and support factors from onset of illness through to end-of-life care.

# Methods

- ▶ Focus group interviews were undertaken with disability support workers from four rural locations in NSW and Queensland (one small rural town and one larger regional centre for each state).
- ▶ A semi-structured interview guide was used, with a focus on gaining an understanding of the barriers and impediments to providing appropriate and timely end-of-life care for individuals with intellectual disability.
- ▶ All focus group data were independently transcribed, with thematic analysis then performed.

# Summary of Results

The thematic analysis identified eleven key thematic areas under three over-arching levels;

- ▶ **Government**, including community infrastructure and generic health services access,
- ▶ **Organisation**, which included internal policy & practice restrictions and poor staff training, and
- ▶ **Individual**, such as religious beliefs, personal relationships and end-of-life expectations.

The focus of this presentation will be primarily on issues arising from the themes of **Government** and **Organisation**.

# Summary quote for Results

*“I am going to be brutally honest ...with 15 years of experience in disabilities, this is beyond me as a manager. This is, I believe, beyond my level of skill and clinical decision making”*

# Results

Some positives to being with;  
What is working?

# Collaborative Approaches

(Theme: Organisation)

- ▶ A collaborative approach, with all key stakeholders being involved.
- ▶ A very carefully planned and structured model of support that considers all available options and possibilities.

*“it happens early, before we are talking palliative care, we have mum, dad, whoever, any family member who wants to be involved, so they’re aware of medical stuff that’s going on”*

*“it was because there were so many staff there that care for her on a day to day basis. If they weren’t there, we could have had our own little conference but it wouldn’t have achieved the same level of information”*

# Health and Pharmacy Support

## (Theme: Government)

- ▶ There were reports of very positive experiences in terms of the support from both government and community health specialists and pharmacists.

*“We had a lot of help from the palliative care nurses here in \*\*\*\*\* and they were all fantastic”*

*[Medical practitioners are good at] “explaining new medication regimes when they are coming out of hospital, advising us that this can work, this won’t work, how we are going to go about it”*

*“Pharmacists provide ... advice on medication, from systems, to information about the different drugs, and suggestions ... they are just invaluable.”*

# Staffing

(Theme: Organisation)

- ▶ In general, the direct care staff are very supportive of the process, are keen to contribute, and are willing to assist individuals to stay at home as long as possible.

*“I know for one [an RN], I learnt a lot about her care during that conference”*

*“it was pretty much agreement across the board as to what she was up to and what was needed next”*

*“The staff just suck it up and keep going”*

# Findings

So, what is not working  
so well?

# Lack of Choice / Services

## (Theme: Government)

The lack of choice, often due to a complete absence of services, in rural communities was a key message that kept arising.

This applied to accommodation options, medical and allied health care (including counselling support).

*“You can say what you want but if the choices are this or nothing ....”*

*“if you are talking about in [a rural town], that could come to the point where the person is not even given the choice ... they may end up in any aged care facility anywhere. There may be no choice at all.”*

*“we knew that we couldn't actually provide that to our clients....when we went looking ... we couldn't find anyone”*

# Health Support

(Theme: Government/Organisation)

While some health practitioners were very supportive, others were less open.

Many struggled with exactly how to best support the individual.

*“They then sent her home because they couldn’t cope”*

*“communication from her GP happened independently of any information that we provided around what we could or could not do. We weren’t asked what we could and couldn’t do.”*

*“I think he has the best of intentions ... it is just a bit difficult ... I think even he is struggling to know exactly what her understanding of different issues is.”*

# Staffing Issues

## (Theme: Organisation)

- Disability staff (in general) are not used to providing end-of-life care, and many staff have been supporting these same individuals for many years, and in some cases, decades.
- Some staff report both emotional and skill-based difficulties in providing care during the end-of-life stage.
- In particular, staff lacked confidence in providing basic counselling support. This magnified the issue relating to a lack of services.

*“there’s a high turnover of staff, and continuity of care can be very difficult”*

*“we did have one staff member who didn’t cope very well emotionally with some of the issues.”*

*“It would be very difficult to upskill people quickly to palliate people to the end .... if they were starting from scratch.”*

# Consent Issues

(Theme: Government)

There appears to be a lack of clarity around consent issues, particularly for individuals with moderate to severe intellectual disability or communication difficulties.

## What Is Informed Consent?

“Consent given by a competent individual who

- ❖ Has received the necessary information
- ❖ Has adequately understood the information
- ❖ After considering the information, has arrived at a decision without having been subjected to coercion, undue influence or inducement, or intimidation”

*“the GP that said he believed that the client didn’t understand the diagnosis and treatment options, and that he doubted her ability to give informed consent or withhold consent.”*

*“the same GP also said the same person was within their rights to refuse their blood being taken. It’s a bit of a contradiction.”*

*“Capacity is not an absolute thing, is it? Do they have the capacity to make this particular decision within the context of all of all this bigger stuff that needs to be decided?”*

# Funding Issues

## (Theme: Government)

There is a significant impediment in that ageing, disability and health funding is differentiated between disparate state and commonwealth government departments.

This artificial divide can result in the forced movement of a person into a residential aged care facility on the basis of funding changes, not individual need.

*“She turned 65 last week ... up until that point we were kinda using her funding in a semi-flexible sort of way, but it doesn’t exist anymore.”*

*“The funding body’s recommendation ... was to consider at what point should she transfer to ... an aged care facility.”*

# Funding Issues

(Theme: Government)

*“There is a lot more support out there in the community for the normal ageing population now. There’s a lot of different packages and that, particularly for those who get dementia and get to remain in their own homes for as long as possible. Whereas this client cannot access those packages because she lives with us, and yet we are not getting the funding to provide as much as one of those packages would for her.”*

# Conclusions

- It is already known that access to services is often poor for rural residents.
- However, these findings indicated that rural people with intellectual disability are further restricted in their ability to access generic and specialist services during their end-of-life.
- Exemplars including the lack of counselling support, and access to appropriate residential options. Improved access to end-of-life services is urgently required in rural areas, with a need to consider implementing innovative care models.
- Development of specialist training and support models for both disability and general healthcare staff may assist to reduce some identified barriers.

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