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Maintaining quality of life for people with intellectual disabilities during end-of-life in rural areas of Australia

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Abstract:	Changing disease patterns and improved life expectancy have resulted in a growing cohort of older Australians with an intellectual disability, with the provision of end-of-life care to this group only recently emerging as a priority area. Particularly in rural settings, where the availability of both specialist and general local services may be limited, end-of-life care support remains under-explored. The current project aimed to specifically examine end-of-life care provision in rural areas, with the focus of this paper on individual quality-of-life during the end-of-life stage. The study used a focus group interview model with 22 rural disability support workers from either NSW or Queensland who had direct experience in providing end-of-life care. An advisory committee, composed of people with intellectual disabilities, carers and service providers, offered overall project guidance. Participants elaborated about factors that contribute to quality-of-life during end-of-life care. Verbatim transcripts of these focus groups were then thematically analysed by the team. The analysis identified three thematic categories: availability of services, individual needs, and untreated pain. Specifically, participants noted concerns about the unavailability of health services, inflexibility of funding support, artificial government barriers and a widespread lack of pain relief for individuals. We conclude that end-of-life support for rural people with intellectual disability has to trade-off the ongoing delivery of quality-of-life activities against the increasing need for health care, which itself is subject to accessibility issues, and which is exacerbated by the more general funding challenges seen across all locations with the NDIS implementation.

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Maintaining quality of life for people with intellectual disabilites during end-of-life in rural areas of Australia

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Abstract:
Changing disease patterns and improved life expectancy have resulted in a growing cohort of older Australians with an intellectual disability, with the provision of end-of-life care to this group only recently emerging as a priority area. Particularly in rural settings, where the availability of both specialist and general local services may be limited, end-of-life care support remains under-explored. The current project aimed to specifically examine end-of-life care provision in rural areas, the focus of this article being individual quality-of-life during the end-of-life stage. The study used a focus group interview model with 22 rural disability support workers from either New South Wales or Queensland, who had direct experience in providing end-of-life care. An advisory committee, composed of people with intellectual disabilities, carers, and service providers, offered overall project guidance. Participants elaborated on factors that contributed to quality-of-life during end-of-life care. Verbatim transcripts of the focus groups were thematically analysed by the team, and three thematic categories identified: availability of services; individual needs; and untreated pain. Specifically, participants noted concerns about the unavailability of health services, inflexibility of funding support, artificial government barriers, and a widespread lack of pain relief for individuals. We conclude that end-of-life support people with intellectual disabilities in rural areas has to trade off the ongoing delivery of quality-of-life activities against the increasing need for health care, which itself is subject to accessibility issues, and which is exacerbated by the more general funding challenges seen across all locations with the National Disability Health Insurance implementation.

Keywords*: rural; remote; end-of-life; quality of life; intellectual disability; service delivery; palliative care*

Individuals with an intellectual disability are now consistently living into adulthood and beyond (Arvio et al., 2017; Bittles et al., 2002; Glasson et al., 2002), with a changing age

profile resulting in the emergence of many non-communicable diseases previously uncommon in this cohort (Sullivan et al., 2007; van den Akker et al., 2006). Improved longevity and new disease patterns specifically related to ageing now require proactive end-of-life care)i.e.. support provided to those individuals with medically-identified. prolonged life-limiting illnesses (Wiese et al., 2012). However, knowledge gaps exist with respect to maintaining the quality of life of people with intellectual disabilities with emerging end-of-life support needs. Indeed, the intellectual disability sector has only recently started to identify end-of-life care as a priority area (Read & Todd, 2010; Todd, 2013, Weise et al., 2013a; Hunt et al., 2019).

Existing research has identified key problems that act as an impediment for individuals with intellectual disabilities in accessing end-of-life care services (Wiese & Tuffrey-Wijne, 2020), including the availability of important palliative care support, such as appropriate and timely pain relief (e.g., Wark et al., 2016). This, in turn, results in sub-optimal care provision (Read & Elliot, 2007; Read & Todd, 2010; Todd et al., 2013). Government policy and practices have not yet adjusted to this emerging need, and there remains ongoing uncertainty as to how best to support quality of life outcomes during end of life for people with intellectual disabilities (Wiese et al., 2013b; Wiese et al., 2015, Hussain et al., 2019).

Within this wider context, it is worth noting that most of the pioneering research in Australia has been undertaken in metropolitan areas (see work by Wiese, Stancliffe, Dew, and others), and these issues have not yet been well explored in rural settings. It is known that intellectual disability research often overlooks the impact of rurality of individuals (Wark, 2018) with key differences in the availability of support options, such as the lack of specialist local services (Wark, Hussain & Edwards, 2013). In a specific attempt to broaden the knowledge base about needs of people with intellectual disabilities outside of metropolitan settings in Australia, the focus of this article was to scrutinise the issues that impact on perceived quality-of-life during the end-of-life stage for people with intellectual disabilities through the lens of direct-care staff.

Method
Research design
To best explore the issues perceived to impact on individual quality-of-life during the end-of-life for people with intellectual disabilities, this project was structured to incorporate a diverse range of settings and viewpoints, and utilised a focus group interview model (Richie et al., 2014) as the study methodology. This group approach was chosen to facilitate broader discussion and consequently develop a more nuanced consideration of the factors than in individual interviews. Before commencement, an advisory committee composed of people with an intellectual disability, carers, and service providers was established. This committee advised the project team about the rural locations to be potentially included and assisted in the development of the interview guide for the focus groups. The advisory committee met several times via online technologies and provided recommendations to the project team. Ethical approval for the project was granted by the University of New England's Human Research Ethics Committee.

Participants and recruitment
The advisory committee compiled a list of possible locations in both NSW and Queensland it considered appropriate for a diverse sample of potential participants. Further discussions led to the final selection of four locations, which included two rural towns, a large rural town,

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and a regional centre (Department of Health, 2021). Two rural towns, one each in New South Wales and Queensland, were included on the advice of advisory group members, who felt that experiences could vary substantially between smaller rural locations, and therefore desirable to include more than one site. The exact locations remain de-identified to ensure the anonymity of respondents in smaller communities, but all are situated more than a 90-minute drive from the nearest metropolitan area.

Participants were recruited from rural disability support services through purposive sampling, using a typical-case model approach (Palys, 2008). In Australia, disability accommodation services are provided generally through non-government organisations (National Disability Insurance Scheme [NDIS], 2021), with health services provided through the relevant state government or community providers [e.g., General Practitioners]. All intellectual disability support services were identified in the four locations, and members of the project team contacted each separate organisation to ascertain if they had provided end-of-life care within the past three years and, if so, if they were willing to allow their staff to participate in the current study. Four organisations, one in each location, confirmed their eligibility and agreement to participate. Information packages were then sent to each organisation for distribution to all staff members, who could subsequently contact the research team independently to indicate their interest in participating. Inclusion criteria for potential participants were that they had supported an individual during their end-of-life and were currently employed by a disability organisation. The size of each focus group was pre-nominated to be between 4 and 12 participants (Sim, 1998), and potential participants were advised that numbers would be capped at this upper limit, but this was ultimately not required.

Focus Groups

A semi-structured interview guide was developed and revised with input and feedback from the advisory committee. All questions in this guide were premised on specifically exploring the participants' perceptions of the end-of-life experience of individuals with an intellectual disability. An example question from the interview guide was "What do you see as a 'good end of life'?", with additional prompts to deepen the discussion around quality-of-life issues for people with intellectual disabilities in terms of their social networks, daily activities, living arrangements, health, and religion or spirituality. To ensure confidentiality, the guide did not include any questions on age or the participants' educational background.

In the prior information session, all potential participants were advised that the focus group would run for approximately an hour, but mutual agreement could allow more time. Consent for audio-recording was sought with the option to pre-select a pseudonym before the recording began. At commencement, it was verbally confirmed that each participant met the inclusion criteria for this study. The interview guide was used to initiate dialogue; the subsequent interactions and issues raised among the participants became the prime drivers for group discussions. Two research team members were present at each focus group. Each of the researchers completed separate field-note summaries following each session to assist with subsequent transcription and data analyses. Ultimately, there were 22 participants in four separate focus groups comprising 4, 5, 6, and 7 participants respectively. There was an evident gender bias, with more than twice as many females as males [15 females, 7 males]. However, this imbalance generally represents the Australian disability workforce (Martin & Healy, 2010). The length of focus group sessions ranged from 31-73 minutes.

Data analyses

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The recorded discussions were independently transcribed verbatim, with the output text using either participant- or researcher-nominated pseudonyms. As part of the member checking processes (Charmaz, 2006), copies of their transcribed group discussion and overall thematic analyses were then provided to four focus group participants. Each participant was asked to review the veracity of the transcript, which was confirmed. A thematic analysis methodological approach (St John, 2004) was chosen to analyse the data, using the framework of Braun & Clarke (2006). Data analysis was undertaken by hand, with each researcher independently reading the transcripts to familiarise themselves with the content and then developing preliminary thematic codes. The entire team discussed these to generate the near-final coding schema for the collated data before review. The complete thematic analysis used this coding structure to refine the data into the core thematic areas.

The participants who had previously checked the veracity of the transcripts were further asked to consider the thematic analyses in light of their perceptions and perspectives as well as concepts of credibility and usefulness of the analysed data. Participants were advised that their specific comments would be included in the revised analyses and future outputs, but all expressed their satisfaction with the process, and no changes were suggested.

Findings and learnings

Data analysis identified the three thematic categories: availability of support; individual needs; and untreated pain. Key findings have been presented sequentially in the following sections for each of these three themes. Asterisk strings have been used in direct quotes to avoid the potential identification of individuals, locations, or services, or both.

Availability of support

Availability of support related to comments, concepts, and ideas that referred to the provision of health support services for people with intellectual disabilities during end-of-life, and the impact on their quality of life that the delivery of this care could cause for the individual.

Focus group participants across all four groups reported that necessary health, palliative, and specialist end-of-life care services could not be easily accessed within their local communities. This, in turn, necessitated the individual having to travel significant distances to either a major centre or capital city. Carolyn, [rural town] noted explicitly:

> We had a client with lung cancer …. what we found was really hard was shoving him back-and-forth from ******** to the oncology over there, to see the specialist. That was really, really hard to travel …. just travelling to ******** was the hardest, I think.

All focus groups considered the requirement to travel for medical treatments to impact negatively on quality-of-life. When the individual was already unwell, taking long car trips for treatment added to their discomfort. Carolyn further noted that they had had to adopt different strategies to address this issue, even on trips of around one hour: "We had little breaks, and he used to have a cigarette, so we had our little breaks where we used to stop." Additionally, the time involved in travelling to appointments reduced the capacity of the service to support "enjoyable" quality-of-life activities, because the limited individual funding package was instead spent on health care. Stephanie [rural town] explained that travel was unfortunately necessary for rural areas, but costly: "And it was expensive, but you know, it had to be done … [to] see the specialist. So yeah, that was probably the worst, I think. The travelling."

Strategies to combat issues associated with rural travel were also discussed. They included "the need to think laterally", and to use whatever alternative local resources were available to complement external health care. For example, Susie [large rural town] outlined how they used a local pharmacist, particularly after a video consult with a specialist, to explain the rationale for any new drugs and what side-effects to monitor to limit the impact on quality-of-life. She stated that the pharmacist could provide:

> Advice on medication, from systems, to information about the different drugs, and suggestions and they are just invaluable, 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.

Another support issue pertained to a legal guardian's role in making decisions around the provision of services during end-of-life. A commonly reported perception was that independent guardians appointed by the Guardianship board were not fully aware of the individual's situation due to the fact that they were often located in another town or city. It was suggested that this lack of familiarity resulted in some guardians trying to "second guess" the recommendations of the medical professionals who were more familiar with the case.

> Umm, I was totally disappointed with the Guardianship Tribunal. When he went to have an operation, they spent about an hour-and-a-half asking why, and the surgeon's there saying, "Because he has bowel cancer. We need to get in there and do something." And it was just as if, you know, they knew more than what the doctors did, and I found that really disgusting …. that they were trying to go above a surgeon. [Stephanie, rural town]

At the same time, the need for an independent guardian was strongly supported. It was agreed that a checking mechanism was needed to ensure that the medical care being provided was actually necessary and would either increase or maintain quality of life. This was explicitly noted by Carolyn [rural town], who felt the review process was valuable. She stated:

> They'll question whether you're putting a client through unnecessary stress by having an operation when the outcome may not actually extend the quality-of-life, only the quantity of life. So that's where some of those questions do come up.

Mental health associated with end-of-life for people with intellectual disabilities also emerged as an issue in the interviews. When asked to provide an example, Carolyn described a situation in which a man had had to retire from supported employment due to his terminal illness. However, with no alternative activities outside of the house, he developed depression. "Well, he did retire … he was bored – and that was what happened. He was getting quite depressed … spending a lot of time in bed". Carolyn further explained that the individual was subsequently supported to attend a day program, even though no specific funding was available, and this outcome helped improve his quality-of-life: "I thought, well, this particular group of people are the people that he associates with the most – and so it was sort of – he was gradually brought back in, and he's just gone from strength to strength."

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Even though an individual may be in the last stages of life, staff still identified how healthcare improvements could dramatically affect quality-of-life during their final days. For example, Claudia [rural town] noted a specific example where an individual had a cataract operation:

> But she only had her sight for a number of days before she died … she had the operation, I think, on Tuesday, and then she died the following Monday … it was so exciting that she could see again. It was really wonderful.

Lucy [rural town] commented that just having a good doctor improved quality-of-life. When probed, she explained that visiting the doctor could be seen negatively by some individuals, and an increased need for regular visits would significantly impact personal happiness. Lucy noted that one person's doctor made an effort to connect during the end-of-life stage genuinely: "He still always spoke to her as a person … she liked him. She liked going, and she was happy to go to the doctor." This was supported by Megan [rural town] who noted one of the strengths of living in a rural area was the fact that doctors built personal relationships with their patients:

> We're very lucky in country areas with our doctors. They see people in the community. They don't just sit in the doctor's surgery. They acknowledge them, they talk to them. It's really important, because we are part of the community just like anybody else ... I don't know whether that happens in Sydney at all.

However, concerns were also raised about some doctors focusing solely on medical needs at the expense of the broader quality-of-life issues. Cassie [large rural town] described one doctor (see quote below) who was insisting that an individual be moved to an aged-care facility. This resulted in the individual actively avoiding treatment, diminishing her quality-of-life due to the doctor's disregard for her views:

> The client is very clear about her wishes to stay at home with her husband … the pressure from the GP is "you will go to an aged-care facility at some point". He has pushed her to the point where she says things like "I'm fine, I don't have cancer, I'm perfectly healthy", so it potentially has gotten in the way of her accepting what her diagnosis is.

Individual needs
While the impact of living in a rural area sometimes manifested in difficulties in accessing health services or supports to maintain quality-of-life, the second theme identified in this study extended the concept to include the broader issue of individual needs beyond just difficulty in accessing health care for people with intellectual disabilities. For example, Robert [regional centre] acknowledged that meeting the basic day-to-day health requirements was important, but felt that this alone was insufficient:

> I think quality-of-life is – and all you can do is look back on the residents who have died, in the house, who we've supported … that if they're just supported within their house and their needs are met, day-to-day needs of security, food, and all that, and their personal care and everything, that's only a small aspect.

Robert then went on to comment that there was a strong need to support activities that brought joy or a sense of achievement, even during end-of-life:

> To get out and do something they want to achieve – you know, go down and walk on the beach and feed the birds, or anything – like playing football, watching football – … they come back and thank you for being there, and it does mean a lot to them. Yeah. It's like, we go out and more-or-less take things for granted. "I went to Sea World." "OK, that was good," … but to them, it's a huge thing when that happened.

Practical alternatives were also discussed concerning how to address the issue of individual needs. Even simple changes during end-of-life, such as transferring to a more suitable bedroom that was still within the same house, were considered to contribute to personal happiness. The following interaction from a rural town focus group was an example of how moving a person to a new room improved quality-of-life.

> So as soon as it became available, yeah, that was the first thing we asked ********. Would she like to? Well, she jumped at that. [Claudia,]
> Her room was her sanctuary and her place, so to have the toilet and everything there: wow! That's good! (laughter) [Jane]
> With pink curtains and everything! [Claudia]
> And it was a room that she absolutely adored, because it was right for her. [Jane]

In describing how to best support the non-health-care needs of individuals during end-of-life, Robert [regional centre] stated that the personal touch was vital for maintaining quality-of-life:

> That's the quality of care. The touch on the hand when someone's dying, you know, just to be with them, to talk with them, and even if they're limited in ability, but just to be there and have that contact is – and just to take them out, you take them places and give them their food, assist with feeding, it's all that, but that's the personal hands-on stuff. There's far more – it has a huge impact on the way they're feeling, and even on their health.

There was also discussion around whether the NDIS would assist in addressing individual need. Some participants were optimistic about the NDIS in relation to end-of-life care, and felt that it may help to maintain quality-of-life: "But that, actually, is what the NDIS may...yeah, so there could be the benefits of the new system, because it's one person they're funding, and a plan, which we would hope would be reviewed, and people having different roles, and that support" [Carolyn, rural town]. She went on to say:

> Right now we're talking about people. My plan, my life, we're talking about, and so I think that a lot of the new staff that are coming in are seeing people not as just a client; these are people they are supporting, and so I'm hopeful that that will bring about a more person-centred approach, so you actually have people that really do want to make sure that this person lives their life, not only now, but right to how that is.

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However, some participants felt that the NDIS system could not respond quickly enough to the rapid changes during the end-of-life stage. Lucy [rural town] commented about the NDIS inflexibility:

> It's spreading across the NDIS world, when people have a package they're on, their assessed need is at that time, that's all they're going to have. So where does that extra, you know, come from where you say, "Today, he's not doing so well. He's going to need to be home." Where is that factored in? … You can't be rigid, because people's lives are what they are.

These problems were considered to be often due to artificial barriers created by government policy guidelines. Bronte [large rural town] described her frustration with funding barriers impeding individual's accessing services that would maintain their quality-of-life. In particular, she felt a sense of discrimination as she perceived the mainstream community could access support to remain in their own home far more quickly than people with intellectual disabilities:

> There is a lot more support out there in the community for the normal ageing population. There's a lot of different packages … particularly for those who get dementia 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.

This problem can result in individuals being moved out of their long-standing home, simply due to their individual ageing needs at that point in their life, and that adversely affected their quality of life. One participant [Arthur, regional centre] provided an example where an individual had to move from a disability group home to an aged-care setting as that was the only other support option available in that rural location. This move resulted in the individual experiencing a dramatic reduction in social engagement: "From what I've heard from the mother, all she does is sit in bed all day. She said [mother] ... the support we were giving her was so much better than she's getting." Sam [regional centre] argued that this process of moving is very traumatic during the end-of-life stage for individuals: "It can be quite terrifying when you're taken out of familiar surroundings and put somewhere, where people who obviously don't know anything about you."

Unmanaged Pain
The last theme that emerged from the analyses related to how an individual's pain was managed, or, more accurately, how their pain was *not* well managed. Although this theme is associated with the previous two themes, it requires separate recognition as a critical aspect of supporting quality-of-life for people with intellectual disabilities during end-of-life care. There was less discussion in the forums around this theme than the previous two, but this was mainly due to the widespread agreement of its importance. Specifically, the failure to adequately manage pain through health service intervention was seen as a significant impediment to maintaining quality-of-life and meeting individual needs. Lachlan [regional centre] said that the issue that contributed most to overall quality-of-life was being "pain-free". This was considered vital, as it was recognised that many individuals would obviously

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be in considerable pain during their end-of-life: "in ********'s case, with liver disease, he was in an extreme amount of pain, a lot of pain" [Sarah, regional centre].

The primary concern was identifying how and when to provide pain relief, particularly for individuals with limited communication skills. Stephanie [rural town] explained the difficulty in making this judgement call: "When do you get them pain relief? Because a lot of our clients can't express pain. We just didn't know whether we were giving enough pain relief." Stephanie went on to describe a specific situation:

> … my worst fear was, he was in such pain and I couldn't tell because he was non-verbal, and he was a sick man … are we giving him enough? And that was the biggest thing. And then I thought we were doing the right thing by the patches, and then the palliative care nurse said, "Oh, no, it wouldn't be anywhere near strong enough." So this poor bugger's been in pain.

When discussing whether there were any specific recommendations to overcome this problem, Stephanie then noted a need to be more proactive with the doctors:

> they get sent home with no pain relief, so I say to people who support them …"Argue, and say, 'I want strong pain relief,'" especially for a major operation. Because they do get sent home with nothing. I don't think doctors think. "Hello? They do have pain!"

Discussion
Only limited focus has been placed on understanding how quality-of-life may be affected during end-of-life for people with intellectual disabilities, and particularly in relation to rural residents. The purpose of the current study was to explore the issues, as perceived by support staff, that most impacted individuals' quality-of-life during end-of-life. The analysis identified three key thematic areas: availability of support; individual needs, and unmanaged pain, and the issues associated with these themes.

The focus groups all reported limited access to support services. This is not a surprising finding as it has been previously identified as a significant impediment associated with rural living for people with intellectual disabilities (e.g., Dew et al. 2014; Wark et al., 2019). However, the urgency of access can become far more critical during end-of-life, and therefore the lack of local essential services in rural and remote locations becomes even more significant (Wark et al., 2017). Participants described how unavoidable travel to appointments in other towns or cities had a significant impact on individual quality-of-life. While discomfort associated with long-distance travel itself was an issue, it was additionally problematic simply due to the hours spent travelling to and from health care within rural settings came at the expense of quality-of-life activities.

The second aspect of service access that was identified related to the ability to access local community-based supports to assist an individual in remaining in their own home or maintaining their normal routine activities during their end-of-life. It was considered that there were few specialist services to help individuals and that sudden movement into aged-care facilities was the result for many rural residents (e.g., Wark, Hussain & Edwards, 2015). Even within the NDIS framework, it was reported that there were no easy mechanisms to quickly gain additional funding to support urgent end-of-life care, partially due to the explicit

separation between disability support and health care (NDIS, 2020). Participants identified that, without new sources of funding, the individual's emerging health needs meant that they were unable to continue to be supported to undertake activities they had previously enjoyed. This could then lead to a downturn in the individual's mental health, which added to the complexity of care and sometimes necessitated accessing even more external support services that are often limited in rural locations.

The role of independent guardians appointed by the Guardianship Division of the New South Wales Civil and Administrative Tribunal was raised as both a concern and a strength. As a consequence of both the emerging medical needs and age of many recipients of end-of-life care, independent guardians are sometimes required to be appointed as the individuals often do not have living parents or relatives to act in that capacity (New South Wales Government – New South Wales Trustee and Guardian, 2020a; 2020b). This approach is standard across all geographic settings. However, it was suggested that rural residents would often have a guardian appointed who is physically located in another location, such as a regional centre or even a distant capital city, instead of the same town, as no one locally is either willing or had been prepared in advance to perform this role. While independent guardianship for vulnerable people was seen as being valuable and necessary, this geographic separation for rural residents led to a perception that guardians were not always fully aware of the individual's needs and desires. This resulted in a belief that not all decisions were necessarily made from an informed position and by taking into account the individual's desires.

Problems associated with the inflexibility of government funding and perceived artificial barriers in accessing services were noted as commonplace. While these issues are likely to be experienced across all areas of Australia, the lack of access to any alternative or even nearby services due to geographic disadvantage have a very clear impact on quality of life for rural individuals with intellectual disabilities. In response to these problems, health professionals, such as doctors, sometimes pushed for a premature move to residential aged-care homes. It was considered that this was often driven by good motives to proactively plan for the future. However, failing to listen to and consider the individual's desires became problematic for the ongoing provision of care.

Limitations
The study was designed and undertaken with a specific focus on four rural sites in two states of Australia, New South Wales and Queensland. It is acknowledged that, while an attempt was made with the advisory committee to choose locations considered relatively representative of rural areas initially, experiences will vary depending upon what resources are available in each location. As such, any comparisons to other settings should be carefully considered in light of the local setting and variations in legislation regarding disability and aged care health services, and end-of-life support.

Conclusions and implications
This research revealed several issues of concern particularly relevant to rural areas. It can be argued that these issues are commonly reported across various facets of life for people with intellectual disabilities in rural locations (e.g., Dew et al., 2014; Gallego et al., 2016; Hussain et al., 2019), but the impact of rapidly emerging end-of-life care needs exacerbates these longstanding impediments even further. Currently, services assisting with the provision of end-of-life support for rural people with intellectual disabilities have to trade-off ongoing delivery of quality-of-life activities against the increasing need for health and palliative care, who are themselves subject to significant travel requirements and access barriers. This

situation is then exacerbated by the more general funding challenges seen with the ongoing NDIS implementation. A review of the existing funding models and service access guidelines for essential support services, including guardianship, are required to ensure that emerging individual healthcare needs are not being met at the expense of maintaining quality-of-life outcomes.

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