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REHABILITATION IN PRACTICE

Addressing the barriers to accessing therapy services in rural and remote areas

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Abstract

Purpose: Throughout the world, people with a disability who live in rural and remote areas experience difficulty accessing a range of community-based services including speech-, physio- and occupational therapy. This paper draws on information gathered from carers and adults with a disability living in a rural area in New South Wales (NSW), Australia to determine the extent to which people living in rural areas may receive a person-centred therapy service. **Methods:** As part of a larger study in rural NSW into the delivery of therapy services, focus groups and individual interviews were conducted with 78 carers and 10 adults with a disability. Data were analysed using constant comparison and thematic analysis. **Results:** Three related themes emerged: (i) travelling to access therapy; (ii) waiting a long time to get therapy; and (iii) limited access to therapy past early childhood. The themes overlaid the problems of recruiting and retaining sufficient therapists to work in rural areas. **Conclusions:** Community-based rehabilitation principles offer possibilities for increasing person-centred therapy services. We propose a person-centred and place-based approach that builds on existing service delivery models in the region and involves four inter-related strategies aimed at reducing travel and waiting times and with applicability across the life course.

Keywords

Developmental disability, person-centred, qualitative

History

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► Implications for Rehabilitation

Therapy service delivery in rural and remote areas requires:

- Place-based and person centred strategies to build local capacity in communities.
- Responsive outreach programs working with individuals and local communities.
- Recognition of the need to support families who must travel to access remotely located specialist services.
- Innovative use of technology to supplement and enhance service delivery.

Introduction

Community-based services for people with a disability in Australia are delivered within an evidence-based policy context which states that all government departments and community service agencies should work together to deliver timely intervention that is strengths-based, capacity building and person-centred. Centrally written government policies should apply equally regardless of geographic location, cultural background or economic status. However, the community service sector in Australia is multi-layered and complex with overarching Federal government legislation and agreements informing State and Territory government policies [1–3]. The State and Territory governments directly provide health, education, community, and

specialist disability services in addition to contributing funds to the non-government sector. There are also private providers, as well as community services that support people with a disability. To add to the complexity, each department and organization has its own service priorities, eligibility criteria, and referral pathways [2]. People who live close to state borders may also access services in the adjoining state. Thus, the implementation of policy may be variable within and between jurisdictions.

In Australia and throughout the world, people with a disability who live in rural and remote areas are more likely than their metropolitan-based peers to have difficulty accessing a range of services including therapy in the community provided by speech-, physio- and occupational therapists [4]. In the first instance, there are less therapy positions, on a per-capita basis, available in rural areas than in metropolitan areas, and insufficient positions overall to meet known needs [5]. Secondly, there is persistent difficulty in attracting and retaining therapists to work in non-metropolitan areas [5,6]. In a study into recruitment and retention of 46 rural-based therapists employed in disability services in New South

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Wales (NSW), Australia, Denham and Shaddock [7] identified personal factors, limited resources, and a lack of career development and progression as the main deterrents to rural employment of therapists within the disability sector.

Among the personal factors influencing a therapist's decision to work in a rural area is the extent to which he or she is required to travel and stay away from home in order to provide a service to people with a disability who live in remote locations. For example, NSW is the most populous and centralised state in Australia with an area of 800,642 square km [8] and a population of 6.5 million [9]. Approximately 90% of the state's population is concentrated along the eastern coastal strip, with an increasingly dispersed inland population living in large regional towns with populations of 20–40,000, smaller towns of 1–3000, and isolated rural communities of 1000 or fewer. There are also people living on remote properties many kilometres from their nearest neighbours. Therefore, a therapist working in rural NSW may be required to travel thousands of kilometres a year providing outreach services in diverse geographic and cultural settings.

A lack of allied health professionals in rural locations inevitably influences the ability of individuals with a disability living in those areas to access timely and effective therapy services. There is extensive evidence that early therapy intervention is important to many people with a disability [10–13]. Regardless of age, early and ongoing access to therapy has been shown to improve participation in family and local community activities and to enhance quality of life for both the person and their carers [10,12,13]. Evidence-based best practice principles highlight the need for intervention to focus on individuals' strengths and build their capacity using a person-centred approach [14]. According to the WHO, World Report on Disability [15], "person-centeredness means that individuals are involved in decisions about the support they receive and have maximum control over their lives" (p. 137).

Much has been written about the advantages of adopting a person-centred approach [14,16–20]. Holburn [20] described a person-centred approach as enhancing opportunities for people with a disability to engage in activities of their choice, thereby developing competence and decreasing social isolation. Similarly, Cambridge and Carnaby [17] and Kilbane et al. [16], described a person-centred approach as one that shifts the focus from service-driven to person-driven opportunities. Such approaches are in keeping with Mount's [21] view that in order to operate in a truly person-centred way, service providers need to rethink the organization's internal systems and the ways they relate to the person with a disability, their carers, and other service providers. Furthermore, Mansell and Beadle Brown [22], advocated a change in the way resources are allocated and managed in order to operate in a person-centred way. However, this literature does not address the additional challenges of adopting person-centred practices when working with people who live in rural and remote communities. Access to a mix of disability-specific, generic and private locally based therapy services may be the best way to support a rural-based person with a disability to receive a person-centred¹ service.

This paper draws on data collected as part of a large, 5-year study examining the issues facing the delivery of therapy services in a rural and remote area in order to develop, implement and evaluate new sustainable models of service delivery. The focus is on the views expressed by carers and adults with a disability about therapy service access and the responsiveness of these services.

Methods

Ethical clearance for the overall study was received from the Human Research Ethics Committee of The University of Sydney

(#10–2009/12194). Written consent was obtained from all study participants, interviews were anonymised and all data were kept confidential. Data are drawn from discussions with 78 carers, and ten adults with a disability who participated in an early phase of the large study.

Sampling and recruitment

Maximum variation sampling [23] and snowballing techniques [24] were used to recruit participants. Government and non-government service providers based in rural NSW distributed information sheets and consent forms to carers and adults with a disability. Inclusion criteria for participants were: being a person with a disability 18 years or older or caring for a person with a disability of any age; living in a rural NSW region; being able to give informed consent to participate; and using, having used, or wishing to use therapy services. Those interested in participating contacted the researchers directly and were then given information about the date, time and venue of the focus group or interview. The number of participants was not predetermined. Theoretical sampling [23] strategies were used to ensure the participants represented a diverse range of experiences of caring for, or being a person with a disability, based on gender, age, geographic location, type of disability and living environment. Nonetheless, because participants self-selected to participate, it is possible that those who wished to express their dissatisfaction with services were more willing to participate than those who were happy with the services they received.

Participants: carers (n = 78)

The majority of carer participants were female ($n = 70$) and eight were male. Carers ranged in age from early 20s through to mid 70s with most participants aged between 31 and 60 years. The people with disability for whom participants cared ranged in age from 16 months to 60 years; median age, 9 years. Participants were representative of geographic locations across the region. The persons cared for represented a diverse range of disability types ranging from speech articulation problems through to people with multiple, severe functional and or intellectual limitations due to conditions such as cerebral palsy, spina bifida, intellectual disability and neurological disorders. The majority of carers were providing care to the person with a disability in their homes; however, a small number of people with a disability lived in supported accommodation.

Participants: adults with a disability (n = 10)

Participants who had a disability included four females and six males and ranged in age from 21 to 59 years. Five people lived in a large regional town (population 40,000) and five people lived in small towns with populations of 1–2000. One person lived at home with parents, one lived with a sibling, and the other eight people lived independently or in supported accommodation. These people had a range of intellectual and physical disabilities.

Data collection

Focus groups were chosen as a data collection method because they provide an opportunity for people with similar experiences to share information in a time and cost effective way [23]. A group dynamic occurs as a result of the interaction between focus group participants as they explain their views to the group and question the perspectives of others [25]. Separate focus groups were held for carers and for adults with a disability. Attendance at a focus group was not feasible for all participants given their geographic spread across the region, or their availability at the time of the researchers' visit to a particular geographic location. Therefore, individual interviews were offered to participants

who were not able, or did not wish, to attend a focus group. Focus groups and individual interviews with carers were conducted from March to August 2011 and with adults with a disability from August to September 2011. All focus groups and interviews, which were digitally recorded with participants' permission, were conducted by the first and second authors who are both experienced researchers and practitioners in the disability field.

Carer focus groups, which lasted two hours on average, were held in disability organization offices or in public meeting rooms. Carer interviews were held in the participants' homes or in public spaces, depending on the participants' preferences. Seven carer focus groups ($n=33$ participants) were held at geographic locations across the region to ensure that participants had access to a group without unreasonable travel. The size of the groups ranged from two to nine participants. A further 45 carers were interviewed individually, either face-to-face, or by telephone. Two focus groups for adults with a disability ($n=9$) were held in the meeting rooms of support organizations, and one person had an individual telephone interview. All sessions with adults with a disability lasted approximately 45 min.

Semi-structured guides were developed for use in the focus groups and individual interviews (copies available on request from corresponding author). The guides' content was informed by the analysis of policy documents, literature, and analysis of data from service provider focus groups and interviews. Participants were asked a range of questions about service access including the extent to which they thought services were person-centred.

Data analysis

The transcript data from carers and adults with a disability were analysed separately using thematic analysis and constant comparison as the analytical framework [26]. Each transcript was read and issues were noted on a data coversheet. Once each transcript was reviewed in this way, constant comparison was used within and between transcripts to identify similar and divergent issues. The data were read again looking for patterns related to the age of the participant, the type of disability, and geographic location. Similar issues were then grouped to form emerging themes, a summary of which was sent to participants. The first author conducted the analysis. The themes were then discussed and agreed with the other authors.

Results

Analysis of the carer and adult with a disability data revealed that they shared three common concerns related to therapy service provision in rural and remote areas of NSW: (i) travelling to access therapy; (ii) waiting a long time to get therapy; and (iii) limited access to therapy past early childhood. The themes overlaid the issue of insufficient therapists working in the region.

Participants acknowledged the expertise and commitment of the government, non-government and private therapists who work in rural areas as captured in this quote from a participant: "She's [therapist] so down to earth and so practical and so helpful... I feel like she really empowered me to help [daughter]". However, due to difficulties in recruiting and retaining therapists, participants reported there were not enough readily available or accessible community-based therapy services to meet the needs of rural-based people with a disability. In the words of one participant: "You're supposed to be able to get it [therapy] but the reality is it's just not there, they [services] just don't have the therapists". Indicative of the difference in access to therapy for those living in rural areas compared to those in metropolitan centres, a participant commented: "It's just the difference between country and [city], there is that Great Divide, a real barrier... once you come over that mountain... things change".

Travelling to access therapy

The lack of locally available services and the vast geographic distances in rural NSW mean that people with a disability and their carers regularly travel considerable distances to receive a service. Indeed, travel to access services of any kind, be it health, banking, business or disability, is an accepted part of living in a rural area as described by this mother, who has two children with disabilities: "Every time my kids have needed [therapy], it's a two or three hour trip". Such travel means a considerable investment in time and money by families to cover transportation, accommodation, food, and time off work. Another mother who, several times a year, takes her 3-year-old son to a capital city 6 hours drive from home to receive therapy said: "My husband had to take time off work... so it wasn't easy and it's taken its toll definitely financially... we haven't had to pay for therapy but we've had to pay for the travel and accommodation". In a focus group of adults with a disability, one participant spoke about a friend who, following an accident which left him with an acquired brain injury, "goes to [large regional town 2 hours drive away] two days every 6 weeks to see the physio at [government service] for exercises to strengthen his arms and legs [because of the distance] he has to stay overnight in a motel".

Travelling to receive a service also entails a personal cost, as the needs of other children must be accommodated and being away from home means people and their carers are separated from their usual support networks. A father, whose 10-year-old son requires regular specialist appointments involving both medical and therapy, intervention in a capital city 7 h drive from home, said:

They [both sons] miss weeks of school and it's hard on the little one [son without a disability] because he sort of misses things as well... we try to keep it all together... I mean we do have the option of leaving him here with [his grandmother] but it's just easier to have us all together.

Similarly, a mother said: "Obviously some kids don't like to travel. I'm lucky mine does. But some kids don't travel well and the cost, and taking time off work, or what do you do with the other kids... things like that".

Some families said they felt lucky to have extended family members who assist them to travel. For example, one mother said: "Quite often my mum would travel with us because [my husband] works full time... it was more just [to have] a travelling companion... to share the driving and whatnot". However, for other families without readily available support networks, the financial and personal cost of travel for services is more than they could afford and, as a result, they may limit the number of times their child receives a service. As one mother said:

We're supposed to go every 6 weeks to see one of the specialists but I'm a single mum so I can't afford that. We have phone appointments in between but still its \$200 an appointment and you don't get anything back from Medicare².

For children in the 0–6 age range, therapy is often provided in early childhood intervention services on a regular basis. However, for those who live out of the main population centres accessing regular early intervention may involve significant travel. One mother of a 3-year-old son with a disability who lives in a small rural town said: "We also travel to [mid-sized town] weekly, every Monday, which is a 1 hour drive [each way], for early intervention". Similarly another mother, whose son is now 9 years old, reflected on her experience of accessing early childhood intervention when he was younger: "So we would travel [2 hours each way] to [large regional town] once a week for early

intervention [and] they [service] waived the fees for me because we couldn't afford to travel and pay the fees'.

Travelling for services also impacts on the ability of mothers in particular to engage in full time work and/or study. One mother reported:

I've recently completed my [undergraduate degree]... it was a long slog but I got there and now I want to act on it... but it's unfair of me to go looking for work [because] I'm suddenly going to turn around and ask for 6 weeks off [for daughter to travel to capital city for surgery]... so I'm treading water [and] I can't develop what I want to develop... it [having a child with a disability] has a lot of opportunity costs.

Another mother spends 3 h a day driving her son to and from school from their rural property as the school bus is not wheelchair accessible. As a result of the time she spends doing this she told us: 'I've had to stop my course, my [postgraduate] study'. One of the reasons why people with a disability and their carers are prepared to travel so far and so often is the time they have to wait to access local therapy services.

Waiting a long time to get therapy

Participants reported that people with high priority needs get access to therapy services; however, those who are not high priority might have to wait years to access these services. One mother said she was advised by a speech therapist not to place her child's name on the waiting list because 'I think her [therapist's] words were, 'By the time we get to see him, he'll no longer be eligible''. Nonetheless, some carers understood why waiting times were so long. As one mother said, 'It's just that there is a lack of resources and I think the guys [therapists] here are snowed under with it... I feel for them because they're stretched to the limit, and it would be great if we could get more services in the area'.

This view was supported by the comment from another mother: 'So just trying to get the actual professionals to even consider coming here and staying here is the biggest problem'. While these carers understood the difficulties of attracting and retaining therapists to work in rural communities, others perceived the lack of therapists and resulting service allocation system as letting their son or daughter down. For example, one mother said 'You have to beg for it [a service]... it's degrading for a start'. In a similar vein, another mother reported:

They [service providers] say 'Look sorry we don't have funding for an occupational therapist at the moment' like that's not my problem and it breaks your heart that you think 'well my child wants help and you don't want to help them'.

Carers who could afford it reported using private therapists to work with their child. One mother said: 'I could afford it [private speech pathology]... a lot of people can't. [Otherwise] you're waiting and waiting and waiting and then meanwhile your child's growing up and not having access to all that'. Private therapists are available in some areas but may also have long waiting lists.

Because of the need to wait, another mother said: 'You wait wherever you go; and it's basically the more waiting lists you can get on the better... put up your hand for as many pieces of the pie as you can'. The frustration with the long wait for local services felt by many of the participants was summed up by one mother who said: 'I've given up on local services and have chosen to do what we can ourselves... because I feel like if I'm waiting for the local therapy to step up to where I'd like to be, I'm going to be waiting a very long time'.

Limited access to therapy past early childhood

Limited numbers of therapists were also felt to limit the range of services available within the region. For example, participants reported that once children go to school, and the older they get, the less access to therapy they have. When the child turns 18 and becomes an adult access to therapy services becomes more difficult. One mother said: 'I can understand the philosophy, you know, have an early intervention service, I mean that makes sense, but the realities for lots of family members as they age... they don't get better but the services diminish'.

An older mother whose son is now 31 told of her experiences of moving from the city to the country when her son was a child:

When he was very little in [a city] we did have therapy but not for long because we moved up here [to a country town] when he was 8 and [he got no therapy] from then. [He went to a special school] but they didn't get speech therapy [and] they didn't have any occupational therapy where they should've had all that.

Similarly, a young woman with a disability, now in her early 20s, was 15 when she was diagnosed with a rare neurological disorder. After her diagnosis she was able to access therapy as she explains: 'I started physio at the [service] and that was really, really good [and] I was doing speech pathology at [another service]... I did OT there as well for a bit'. The same participant then spoke of what happened once she became an adult:

When I turned 18 they [service providers] wouldn't see me anymore... I was on the waiting list for [government service] and I kept calling them and they said they had no space for me and after probably 2 or 3 years my general practitioner (GP) rang and asked them why and they said 'We took her off the list' and she [GP] demanded that they see me... they had no intention of ever calling me.

A mother was contemplating a similar scenario for her son as he approached adulthood:

I think therapy services just get harder as well... I mean they're hard when they're little but it gets harder as they get older just trying to find them. And it'll get to the point where he won't have any funding [for therapy] at all. Once they're an adult there's no funding I don't think.

The sister of a 60-year-old man who had received cochlear implants reported that he could not get therapy to help him maximise the benefit of the implants. She was philosophical about this:

I mean he's 60, we're not going to be able to get speech therapists out here for a 60-year-old if we can't get them out here for 6-year-old children who desperately need it... so they're [adults] just so far down the list in terms of getting access to anything... they're definitely off the list!

Discussion

The overall picture painted by participants in this study was that government, non-government and private therapists are valued for providing high quality services. However, due to the shortage of rural-based therapists, many people with a disability living in rural and remote areas experience difficulties accessing therapy services with problematic consequences for people with a

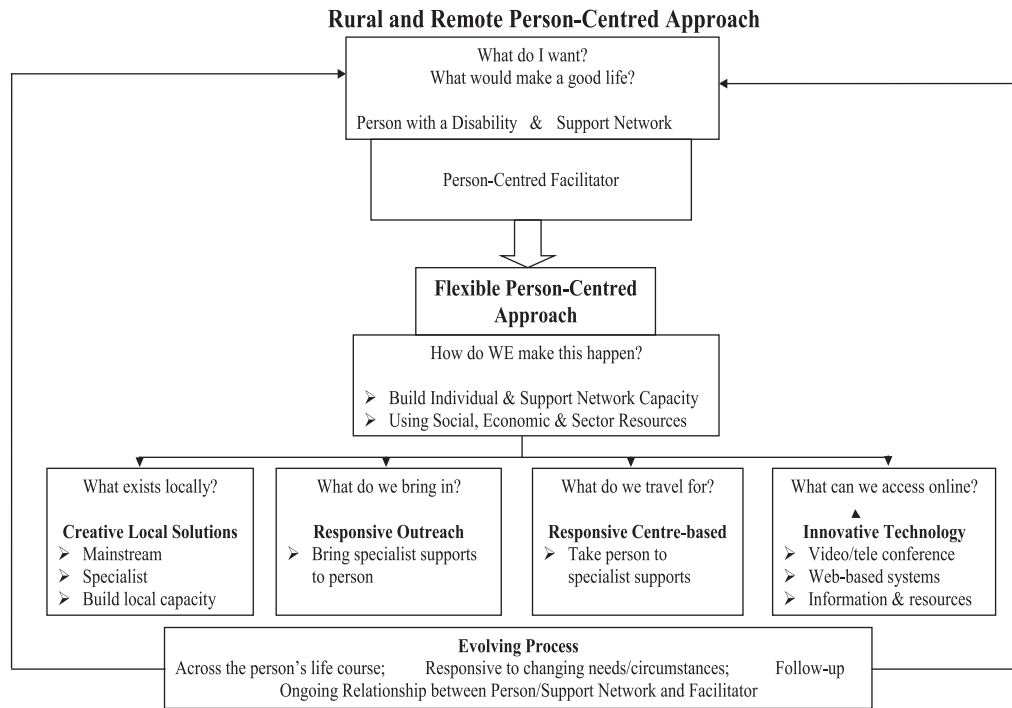


Figure 1. Rural and remote person-centred approach.

disability and their carers. At a local level therapists do network across agencies however, this is not always easy or possible. Furthermore, early intervention services apply to only the youngest children who have the highest needs and, across the life course, interventions are not necessarily building individual capacity and strength. Therefore, for some rural-based Australians, a person-centred therapy service is, as alluded to by Cambridge and Carnaby [17] and Mansell and Beadle Brown [22], more an aspiration rather than a reality.

The literature highlights the difficulties in getting therapists, and other allied health professionals, to work in rural and remote areas [5–7]. In an attempt to minimise therapists' travel and improve service access for people with a disability, rural-based service providers have tried a range of strategies aimed at improving recruitment and retention of therapists to work in rural and remote communities [27]. Despite these efforts, the shortage of therapists continues and people with a disability living in rural and remote communities are disadvantaged as a result [4]. Figure 1 represents a framework to harness the existing supports and develop new options for rural-based people with a disability and their carers.

The approach, that builds on existing rural therapy service delivery options, is person-centred and place-based, and involves four inter-related strategies aimed at reducing travel and waiting times and with applicability across the life course. These strategies have applicability to other community-based services beyond therapy. The starting point for these strategies is the person-centred questions "What does this person or family want?" And "What would make a good life for the person?" Making choices and deciding on the appropriate action to implement these choices is potentially empowering for people with a disability and their support network members [20]. The second key element of this approach is the place-based focus to build individual, carer and local community capacity using available social, economic and community-based resources. Four questions inform the implementation of this approach: (i) what supports are locally available? (creative local solutions); (ii) what supports will need to be brought in? (responsive outreach);

(iii) what supports will the person need to travel to access? (responsive centre-based); (iv) what supports can be accessed via technology? (innovative technology).

What supports are locally available?

Creative local solutions build capacity within existing generalist and/or specialist support providers to assist people with a disability to address the gaps and achieve their desires. For example, we heard of therapists using an active mentoring model [28], to assist a person with a disability to use local amenities such as a gym and swimming pool to meet some of their physical activity requirements. Expanding this approach to work with local councils and community groups could extend the supports available to a person with a disability in a rural/remote location.

Another possibility is training community-based therapy assistants to work remotely in order to implement therapist-designed programs. This approach provides a local solution, and also builds local capacity [29,30]. Assistants are used extensively in CBR and health services but less so in disability services [31–33]. Nonetheless, therapy assistants are an emerging workforce group in disability services who are extending the reach of therapists, particularly in remote locations. Local people who have a good understanding of the geographic, economic and social conditions of the area have been employed in therapy assistant positions. Expanding the number of therapy assistants has the potential to provide a link between a person with a disability and their carers on the one hand, and a therapist who may work many hours away, on the other. A longer-term, local workforce outcome might be that some therapy assistants may be encouraged and supported to train as therapists and, because of their existing links with the community, practice there.

What supports will need to be brought in?

Provision of outreach support has been part of the service landscape in rural areas for many years, with outreach therapists, equipment suppliers and home modification experts visiting the

person with a disability in their home, school or work environment [34]. Nonetheless, the time and effectiveness of outreach supports may be enhanced by the specialists working with the community-based therapy assistants and local therapists to be their ‘‘eyes and ears’’ on the ground in between visits [29,30]. Again, in line with CBR principles, this builds local capacity, as well as providing information and peer support to rural and remote therapists.

What supports will the person need to travel to access?

Not all supports required by the person with a disability will be either locally available or able to be brought in. There are some specialist supports that the person will need to travel to access. In particular, people with unusual or rare conditions may require access to specialist therapy expertise only found in major cities [35]. People living in rural and remote communities require assistance to offset the costs and imposition of travel to facilitate their access to these specialist supports. Additionally, some of the anxiety related to travelling away for support is alleviated by local services liaising with the receiving service before the rural client leaves home.

What supports can be accessed via technology?

There is recognition by carers and service providers alike of the significant potential to use technology to assist in the delivery of therapy supports. There is evidence from the larger project and other studies that technology is currently used primarily for inter-professional communication [36–38]. Increasing use of audio and visual technologies and therapy intervention software applications has the potential to maximize therapy interventions. As families and therapists become more ‘‘technology savvy’’ and communication network capacity increases in rural and remote areas, so the potential exists for therapists to innovatively use technology to provide advice and support to geographically isolated families.

Conclusion

Findings from this study suggest flexible and innovative support models that build on existing options, are tailored to local place-based needs, and promote cross-agency collaboration may help to increase access to person-centred therapy services for people living in rural and remote areas. Further research into the factors that attract and retain therapists to work in rural and remote areas is also required [6,7].

Making the shift from a more service-centred to person-centred approach is, as described by Cambridge and Carnaby [17] and Kilbane et al. [16], a difficult but necessary transition. The shift is supported by government policy [1,2] however, in order to implement a truly person-centred approach to therapy service delivery, particularly in rural and remote areas, further systemic change likely will be required at all levels of service provider organizations. Mount [21] and Mansell and Beadle-Brown [22] indicated that this change will likely impact on resource allocation, internal management systems, and organizational culture. Within the Australian context, person-centred approaches will be integral to the shift to individual funding of therapy services along with the full range of supports required by individuals with a disability [1,39]. The proposed introduction of an Australian National Disability Insurance Scheme [39] provides additional impetus for innovative workforce strategies to meet the anticipated additional demand for therapy. A person-centred approach is an evolving process that is integral to providing therapy support, continues across the person’s life course, and is responsive to the person and their carer’s changing needs and circumstances.

Limitations

This study involved people with a disability and their carers in one, albeit large, rural and remote region of one state in Australia and therefore the findings may not be applicable to people living in other areas of Australia or in other countries.

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Declaration of Interest

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