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Rural Carers of People with Disabilities: Making Choices to Move or to Stay

Angela Dew¹, Vicki Happ², Kim Bulkeley^{1,3}, Anita Bundy¹, Michelle Lincoln¹, Gisselle Gallego^{1,4}, Jennie Brentnall¹, and Craig Veitch¹

¹ Faculty of Health Sciences, University of Sydney

² Carer, Western NSW

³ New SouthWales Family and Community Services, Ageing Disability and Home Care

⁴ Centre for Health Research, School of Medicine, University of Western Sydney

Correspondence to: Dr Angela Dew, Project Manager, Wobbly Hub and Double Spokes, Faculty of Health Sciences, University of Sydney, PO Box 170, Lidcombe NSW 1825, Australia. Tel: + 61 2 93519050. Email: angela.dew@sydney.edu.au

Abstract

When a child is born with, or an individual acquires, a disability in rural Australia, one of the decisions faced by the family is whether to remain living in a rural area or move to a larger metropolitan centre to access support services such as therapy. Understanding the factors that rural carers weigh up in making the decision to move or stay can inform the successful implementation of the National Disability Insurance Scheme (NDIS) in rural areas. Seventy-eight rural carers were recruited to participate in individual interviews or focus groups to discuss access to therapy services. Data were analysed using modified grounded theory involving thematic analysis and constant comparison. Participants made decisions about whether to stay living in their rural community or to move to a larger centre to receive therapy services according to three interlinked factors: personal factors related to their other family caring responsibilities; social factors including their informal support networks of family, friends, and community; and economic factors, including employment and the time and cost of travelling to access specialist services in larger centres. These factors need to be considered in the roll-out of the NDIS to ensure that rural service users enjoy the benefit of a real choice to live in a rural area without reducing their access to support services.

Keywords: carers; rural; disability

Australia's rural population accounts for 30% of the total population and is spread thinly across large distances (Australian Bureau of Statistics, 2011b). When children are born with, or individuals acquire, a disability in rural Australia, they and their carers (service users) face challenges in accessing support services, including therapy (physiotherapy, occupational therapy, speech pathology) (Dew et al., 2012). These challenges are due, at least in part, to the difficulties service providers encountered in providing therapy across large geographic areas to dispersed populations (Denham & Shaddock, 2004; Lincoln et al., 2013). Rural therapy services are commonly delivered by a mix of government

providers, non-government organisations, and private practitioners using a “hub and spoke” model, whereby providers located in larger population centres provide outreach services to those living in smaller and more remote areas (Veitch, Dew et al., 2012). Dependent on proximity to a larger centre, rural service users travel long distances, wait a long time, and receive less frequent interventions than their metropolitan counterparts (Dew, Bulkeley, Veitch, Bundy, Gallego et al., 2013; Doherty, 2007). A consequence of difficulties with service access is the choice carers make about whether to remain in their rural communities or move to larger centres.

In a commentary on the difficulties faced by rural carers, Doherty (2007) highlighted the imperative for premature babies at risk of significant developmental disability to receive early and intensive therapy. Questioning whether rural areas were equipped to provide this level of support, Doherty cited a review undertaken in one rural area of New South Wales in 2005, which identified seven families who moved to get the services their child needed. An additional factor identified as influencing service users’ decisions is negative local service provider attitudes about disability, which can be particularly problematic if there is a lack of choice of alternative providers in rural areas (Iacono, Humphreys, Davis, & Chandler, 2004).

The focus of the National Disability Insurance Scheme (NDIS) is to provide service users with choice and control so that their community participation and inclusion are enhanced (National Disability Insurance Scheme, 2013). However, there are concerns about how the NDIS will operate for service users in rural and remote areas where existing services are limited (Wilson, 2012).

Rural issues are not unique to Australia, with similar difficulties reported by researchers from Canada, the United States, and the United Kingdom (Arksey & Glendinning, 2008; Crosato & Leipert, 2006; Iezzoni, Killeen, & O’Day, 2006; Jensen & Royeen, 2002; Williams & Cutchin, 2002). In a literature review, Crosato and Leipert (2006) discussed the sociocultural aspects of care of elders in rural Canadian communities. They described carers experiencing additional stresses and burnout due to the lack of rural support services. These stresses influence choices about location.

Given the difficulties highlighted in the literature, one of the decisions faced by family carers is whether to remain living in a rural area or to make the move to a larger metropolitan centre in the hope that access to services such as therapy will be more available and regular. This decision involves a trade-off between the rural lifestyle and the potential for greater service access. There is a growing body of literature addressing the factors influencing clinicians’ decisions about whether to stay or leave rural practice (Cutchin et al., 1994; Hays, Wynd, Veitch, & Crossland, 2003; O’Toole, Schoo, & Hernan, 2010), but little has been written about this decision making from the viewpoint of rural carers.

The aim of this paper is to explore the factors rural carers weigh up in making the decision to move or to stay. Understanding these factors will inform the successful implementation of the NDIS in rural areas. This paper draws on data collected as part of a

larger study known as the Wobbly Hub and Double Spokes project, exploring options to increase access to therapy services in rural New South Wales (Veitch, Lincoln et al., 2012).

Method

The larger study received ethical clearance from the University of Sydney Human Ethics Research Committee (#10-2009/12194). The study used mixed methods to collect data on rural therapy services from the perspectives of service providers and service users (Dew, Bulkeley, Veitch, Bundy, Gallego, et al., 2013; Veitch, Dew, et al., 2012). This paper reports on qualitative data from one service user group, carers.

Setting

This research was conducted in the region of New South Wales that lies west of the Great Dividing Range and extends inland to the Queensland border in the north, the Victorian border in the south and South Australian border in the west. This region is known as western New South Wales and accounts for 72% of the geographical area of the State. The estimated resident population in 2011 was nearly 570,000, equaling approximately 9% of New South Wales' population (Australian Bureau of Statistics, 2011a). This population is scattered among large regional towns (e.g., Dubbo, Bathurst, and Albury) with populations of 20,000 to 40,000, smaller towns of 1000 to 3000 people (e.g., Hay and Brewarrina), and isolated rural communities of less than 1000 people (e.g., Wilcannia and Dunnedo). Some people live on remote properties (farms) many kilometres from their nearest neighbours and hundreds of kilometres from towns.

Recruitment

Using maximum variation sampling (Creswell, 2007) and snowballing techniques (Bryman, 2001), carers were recruited with the assistance of government and non-government organisations that sent information about the project to carers. Inclusion criteria were providing unpaid care to an individual of any age with a disability, and living in western New South Wales. All those who expressed an interest in participating were included and purposive sampling techniques were used to ensure that participants reflected a diverse range of experiences of caring for people with disabilities based on gender, age, geographic location, type of disability, and living environment. People interested in participating contacted the researchers and were sent an information sheet and consent form.

Participants

Over a 3-month period in 2011, 78 carers participated in individual interviews ($n = 45$) or focus groups (7 groups of 2 to 9 participants, $n = 33$). Participants were asked to complete a background information sheet; however, not all participants answered all questions. Table 1 provides participant information.

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Data Collection

In order to support participation of interested carers without unreasonable travel, interviews and focus groups were held in various locations throughout western New South Wales. Where face-to-face visits were not possible, telephone interviews were conducted. All focus groups were held in community meeting rooms and ran for two hours. Interviews were conducted in participants' homes or via telephone and lasted between one and two hours. A semi-structured interview guide was developed based on analysis of data collected in earlier stages of the project and literature related to rural health service access. The guide included questions about: availability, accessibility, timing, frequency, and intensity of therapy use; the extent to which the services met the person's needs; and the impact of geography including the cost of travel, the trade-off between where participants lived and their access to a range of services, and use of technology. Focus groups and interviews were digitally recorded with participants' consent.

Data analysis

Digital recordings were transcribed verbatim. A modified grounded theory approach, including thematic analysis, and constant comparison was used to analyse data (Braun & Clarke, 2006). First author (AD) conducted the analysis, which was then discussed with the other authors. Author KB conducted an audit on 10% of the transcripts to verify the identification of themes. Each transcript was read and emerging 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 and to identify patterns related to the age of the carer and person with a disability, the type of disability, and geographic location. Similar issues were then grouped to form emerging themes. One of the themes, reported in this paper, related to the decisions that some carers spoke about regarding whether to stay living in their rural community or to move to a larger centre in the hope of receiving therapy services. Letters and numbers are used to identify the range of carers' quoted.

Results

The second author of this paper (VH) lives in western New South Wales with her 12-year-old son who has Down syndrome. VH's voice is used in this paper to highlight the experiences of carers who decided to move for services. When VH's son was born the family were living in a small, geographically isolated rural town over two hour's drive from the nearest large regional centre. VH described what this was like:

When [son] was born I didn't think his disability would affect where we would live. I had worked in the (health) system and lived in the same community for years. [Son] had no serious complications and I thought if I needed help things would be easy to access, after all [son] had an identified common disability. We live in a modern society don't we? I suppose I was a bit naive. Our family plan had been to move to a town 3 hours further west but I realised that the attitudes

and lack of services we were battling here could be even worse out there. If I was going to move it had to be to a place with more opportunities for [son] and for me. I had to make some tough choices (VH).

Other participants recounted similar stories of having to weigh up a range of factors in making decisions about whether to move to larger centres or to stay in their rural communities. Three interlinked factors were identified as influencing carers' choices: personal factors related to their other family caring responsibilities; social factors including their informal support networks of family, friends, and community; and economic factors including employment and the time and cost of travelling to access specialist services in larger centres.

Personal Factors

All carers, regardless of geographic location, have caring responsibilities other than for their son or daughter with a disability, including other children and ageing parents. A lack of local services and the imposts of travel meant that rural carers reported particular challenges in fulfilling their caring responsibilities. Participants had to weigh up what they believed was in the best interests of all family members. A carer from a mid-size, geographically isolated town explained why her family stayed there, despite the lack of therapy for her preschool-aged son who has significant developmental and physical impairments:

My husband has got three kids from a previous marriage, but we have shared custody with his ex-wife, so they're here every second week for the week. Given my husband's situation...we're not in a position where we're going to move and leave town. (Telephone Interview 1)

Another carer with four children who lived in a small rural town three hours' drive from Sydney described why she made a decision to stop regular trips to the city to access treatment for her 16-year-old son:

It's been really awkward because it's an overnight travel for me and as I said with having the other children and they were just getting out of hand and I sort of had to start weighing it up and saying "something's got to give" and that was it. (Telephone Interview 2)

Similarly, another participant expressed concern about needing to have her other child cared for while she took her 2-year-old son to the city for treatment: "My daughter gets fobbed off to family all the time" (Focus Group 1.3). Care for elderly parents may further complicate carers' lives, as VH described: "My parents lived only two hours drive away but they are aged and with increasingly failing health they have been unable to support us and it is now to the point I am beginning to support them" (VH).

Social Factors

The social environment – family, friends, and the local community – in which participants and their families lived was of great importance to their social and emotional wellbeing. The following quotes demonstrate the experience of one family who moved

from another part of New South Wales where they had regular access to services for their teenage son, who has significant physical and developmental disability, to a small rural town in western New South Wales. The mother explained why they decided to move: “We wanted to be able to afford somewhere that we could not have a mortgage, be on a property, build a house that was going to accommodate wheelchairs” (Telephone Interview 2). Despite the lack of therapy services in the town and their need to travel regularly to Sydney and larger regional towns to access it, this mother said:

We enjoy life out here. There’s no way we’re going to move back to a metropolitan area. So if we have to go to [Sydney] every three or four months well then we’ll do that. But we’ve the life out here that we want....we’ve gained more than we’ve lost. (Telephone Interview 2)

When asked what she meant, she replied:

That’s one thing I’ve found about [town]...when we first came out here we ended up with people coming up and just starting to talk to us and we’d never had that before and they’d come and talk to [son] “Oh, how are you going?” It took us a little while to realise that that’s just country folk, that’s exactly the way they are. The kids [with disabilities] are a part of the community and you know that the people are going to look after them. It’s just so different. (Telephone Interview 2)

This family made the decision that the benefits of a small rural town – that sense of community – at this stage outweighed the benefits of more accessible therapy for their son. Similarly, another mother spoke about her family’s decision to stay living in a small rural town after their now 10-year-old son was born with a significant physical impairment:

Well, a lot of people said to us from day dot [birth of son]...should you move to [Sydney] or [regional city]? But we knew this was the best place for him. Even though we’ve had to travel and fight for his services...he’s been in a little community that’s fully supportive. (Individual Interview 2)

Similarly, a mother with a 23-year-old daughter said: “I don’t know why people want to cluster into cities...there are more services available [but] there’s just so many people requiring the services...[moving from city to regional town] was the best move we ever made” (Focus Group 2). The size of rural towns can be a double-edged sword. On the one hand, small size can mean a close-knit community but on the other, services are few, as explained here:

[son is] the only child with Down syndrome [at the preschool] and because everybody knows [him] like because he's there now...he'll be treated normally and...it's such a small community, you know everything before it happens anyway [but] with that comes the lack of services. (Focus Group 1.3)

However, VH spoke about another side to small rural communities, where people are perhaps less accepting of difference: “Attitudes [to disability] are better than they used to be but people are still scared of what they don’t know or understand” (VH). Recognising the need for more services as her son grew up, VH said:

I looked at the map, I went on the web and talked to people until I found a place that I thought would have the things we needed. It would be five hours drive from our home town and I only knew one person who lived there but I had to do something. (VH)

Economic Factors

All participants spoke about the additional costs associated with having to travel to access services including time off employment, fuel, wear and tear on the vehicle, and accommodation when an overnight stay was required, as explained by VH:

Access to [specialist early intervention] all depended on how much money we had or what was going on in the family from week to week because there was no compensation for fuel, food or accommodation and it was at least a four hour round trip. (VH)

A carer of a 3-year-old son with Down syndrome, who lives in a small rural town 40 minutes’ drive from the nearest early childhood intervention service, said: “They [therapists] like me to come once a week but we just haven’t got the petrol money” (Focus Group 1.1). Similarly, another carer in the same focus group said: “Well, we’re supposed to go every six weeks to see one of the specialists [in Sydney four hours drive away], but I’m a single mum so I can’t afford that” (Focus Group 1.2).

Participants spoke about the cost of purchasing and maintaining equipment and making home modifications. A father described how his small rural community assisted with some of the expenses associated with raising his 10-year-old son: “Even for our home modifications the town raised \$20,000 to help us pay for that. They didn’t pay for the whole lot but they paid for a fair bit of it” (Individual Interview 3). As a further example of the willingness of this community to assist, the father continued:

Well we looked at a lift for the house and the price...is just enormous...about \$20,000.00. We were really lucky, through family connections we bodgied up one...an old forklift with a cage welded on to the front of it, and we had a friend who’s an electrician so he did all the buttons...and then the forklift company donated the forklift because it was one that they couldn’t use...anymore. Another group donated the cage [and] they made a chequered plate, fully enclosed. So we didn’t end up paying anything for it. (Individual Interview 3)

Participants also spoke about the impact of caring on the ability of both parents to work. Another father who provides full-time care to two primary school-aged sons with disabilities explained:

Sometimes I don’t feel like I’m contributing to the family unit. I know that I am

because of [looking after the boys], but...when you were in a management position and earning good money, you had an income and you feel like you were contributing, and all of a sudden you're not. (Focus Group 3)

Livelihoods associated with rural areas (e.g., farming and mining), either bind carers to their geographic location or result in family separation, as explained by VH: “My husband...found [son’s] diagnosis hard to handle...and he has chosen the majority of [son’s] life to live away from the family home for work supporting us financially” (VH).

VH summed up the hard decisions faced by rural carers in deciding whether to stay living in a small community or to move to a larger centre as she did:

I regret some things in my life but not that [son] has a disability. That has made me the person I am and I’m a better person because of him. What I really regret is having to make decisions with the unreasonable choices left to me just like so many other families because of the lack of services and resources in our market driven society. I’ve had to make some painful and hard-to-live-with decisions but I suppose I had a choice. I chose not to limit my son’s potential and despite everything I’m glad I made the decision to move. (VH)

Discussion

Due to geographic isolation and low population density, rural areas of Australia offer limited support services to people with disability and their carers. Service users face a decision about whether to remain living in their rural area or move to a larger town or city to have more choice in supports - some rural carers decide to move and others to stay. There is no right or wrong decision, as each family weighs up its unique requirements and circumstances. This study identified three interlinked factors that influence the choices rural service users made. Personal considerations around the needs of other family members, such as other children, ageing parents, or grandparents, or a combination of these factors, are not an exclusively rural concern. However, rural factors exacerbate the issues. For example, Doherty (2007) described how some individuals need early and intensive support and when this is lacking in a rural area carers may feel they have little choice but to move.

Social factors associated with the particular rural environment are also important in making the decision whether to go or to stay. As described by participants in this and other studies, small communities offer benefits in terms of close personal connections but this can also have a negative side, with a loss of anonymity and confidentiality (Jensen & Royeen, 2002). Recognising the complexity of rural communities, including a need to balance personal and professional relationships, Jensen and Royeen described the particular need for rural service providers to consider “relationship-centered care that is personal, professional and community sensitive” (p. 127).

Finally, economic factors were identified by participants as important due to the significant additional costs faced by rural carers. United Kingdom researchers Arksey and

Glendinning (2008) identified distance, travel times, and transport as unique imposts on rural carers' pockets. They also described the difficulties carers faced in maintaining employment and their reliance on carer benefits as further barriers with a concomitant impact on carers' sense of personal identity. Further research is required to understand whether variables – for example, how long a person has lived in a particular geographic area – impact on their likelihood of staying or moving.

Implications

The three factors identified in this study that influence rural service users' decisions about whether to stay or to leave rural areas need to be considered in the roll-out of the NDIS, to ensure that rural service users are not disadvantaged and have the opportunity to make real choices about where they live rather than feeling they have little choice but to move to access disability service supports. Undoubtedly, there are social and financial costs to living with a disability in rural areas that should be accommodated within the NDIS. However, there are also benefits to be found in small rural communities that have the potential to be utilised in enhancing choice, control, and community inclusion.

Dew, Bulkeley, Veitch, Bundy, Gallego, and colleagues (2013) identified a rural and remote person-centred approach that has application within the NDIS landscape. Locally available supports can be harnessed to meet service users' needs using individual funding allocated through the NDIS. This potentially means service users can reduce the need to leave their rural communities for services. Support can be brought into small rural communities via outreach provided by regional and city-based therapists. Potentially, there is a greater role for private therapists who may have more flexibility to respond to rural service user's needs in an NDIS framework (Dew, Barton, & Ragen, 2013). Within the NDIS model, rural carers need to be adequately financially compensated for travel to larger centres and cities to access specialist supports. Lessons about financial compensation for rural service user travel can be learnt from existing individual funding schemes (Dew, Bulkeley, Veitch, Bundy, Lincoln et al., 2013). Increasing uptake of innovative online technologies may reduce travel for both carers and therapists by extending the reach of large regional centre or city-based therapists directly into service users' homes (Chedid, Dew, & Veitch, 2013), and must be considered in the NDIS schedule of supports. The need for and use of support services will vary across the person with disability's life course and so options will need to be revisited on a regular basis. As the NDIS rolls out nationally, research is required to understand the impact on the availability of services for people with disabilities and their carers in rural and remote areas.

Limitations

This study included only participants who were living in western New South Wales. Therefore, the views of those who moved to other areas of New South Wales, to a city, or interstate are not represented. The views of those who moved away from western New South Wales about the reasons for their move may be different from the views expressed by participants in this study.

Conclusion

Families will always make decisions based on a range of personal, social, and economic factors. With the NDIS, the ability to offer families more flexible, localised, and person-centred supports may assist rural families to have a real choice about where they live. This will only become a reality if there is a more equal playing field, with reasonable access to a range of local support options and funded capacity to travel to access support when needed.

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Conflict of Interest

Author Kim Bulkeley is employed by NSW Family and Community Services, Ageing Disability and Home Care.

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Table 1. Participants characteristics (N=78)

Characteristic	N	%
Gender (N=78)		
Female	70	89.7
Age (N=74)		
20-40 years	31	42
41-60 years	35	47
61+	8	11
Marital status (N=73)		
Single	11	15.1
Partnered	62	84.9
Participant in born in a rural area (N=74)		
Yes	42	56.8
Time living in western NSW (N=76)		
Range	1-75 yrs	
Average	25 yrs	
Total number of children (N=78)		
Range	1-9	
Mean	2.7	
Age of person with a disability[^] (N=81)		
Range	16 mths – 60 yrs	
Mean	12.5 yrs	
Gender of person with a disability (N=83)		
Male	51	62.20

[^]Nine carers were caring for two or more people with a disability.