

# Adults with disabilities and ageing carers: challenges encountered in a rural environment

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## Abstract


Contrary to the common perception that most people with developmental disabilities die in early adulthood, data from many western countries, including Australia, shows significant improvements in life expectancy for this population. While the marked improvements in survival are a result of significant advances in the clinical care of people with developmental disabilities, especially during childhood and adolescence, their increased survival longevity does not equate with improved physical or mental health. Adults with developmental disabilities experience challenges with such life activities as language, mobility, learning, self-help, and independent living. A significant proportion of these adults live in the community and often their families continue to have a role in their care.

To adequately plan for this population it is important to engage with individuals with disabilities and their families, rather than relying solely on the views of service providers, to identify important aspects of their lives. We present results of a qualitative study, using principles of narrative inquiry, which explored the perceptions of health and social well being of adults with developmental disabilities and family members residing in rural northern New South Wales. The paper also identifies unique challenges faced by ageing relatives, who in addition to providing long-term care for an adult family member with disabilities are themselves likely to experience chronic health problems associated with ageing.

The research provided an opportunity for family members and people with disabilities to articulate the benefits, obstacles and challenges they encountered in accessing services in rural areas. From the data a picture emerged of the needs of this group and how innovative approaches to health management have impacted on them. The participants indicated their perceptions of ageing in place, including what plans and aspirations they had for the future. Their uses of services in the local community, based on formal and informal support networks are described, plus implications for future planning.

## Introduction

The life expectancy of people with lifelong disabilities, including intellectual disabilities, has increased significantly in recent years<sup>1</sup> and it is projected that the numbers living to old age will continue to grow across the world in the next 25 years.<sup>2</sup> The move away from residential (institutional) care has brought a level of responsibility of care back to the families. Many support services are limited to children and/or adolescents and adults with lifelong disabilities can face considerable difficulties in accessing support for training and employment and regular health care. A review of support services for children in NSW reported "problems with access to and availability of services resound across all the reports of rural families and persons with a disability."<sup>3</sup> There is little evidence to support that that the situation is any different for adults. Furthermore for many adults with lifelong disabilities increased life expectancy also requires plans and programs to ensure a smooth transition to some form of non-parental/non-family care. In a large number of cases, such plans or programs simply do not exist.<sup>4</sup>



As these individual and their families are ageing, it is important to engage with all stakeholders to adequately plan, rather than relying solely on the views of service providers.<sup>5</sup> There is some recognition of the value of examining what is happening in the community and recording what people with lifelong disabilities have identified as important aspects of their lives.<sup>6,7,8</sup> However, while there is considerable literature on perceptions of parents of children with disabilities, the voices of older parents regarding the ongoing needs of their adult family member with a disability is largely missing.<sup>9</sup> Previous Australian research has identified the urban viewpoint on such issues,<sup>10,11</sup> but there is limited data that relates directly to people in rural and regional areas of Australia. The aim of this study was to gain an insight into current and future perspectives from people living in the New England Region of rural New South Wales (NSW). We were interested in understanding the context and meaning of everyday life for adults with disabilities. Our particular interest lay in perceptions of their health and ageing, their plans and aspirations for future and the challenges and barriers of accessing formal and informal support networks. A secondary aim was to collect carers' stories from family members in order to gain an understanding of how these individuals made sense of their life experiences.

## Methods

The current study was comprised of two samples. The first group comprised 15 adults with lifelong disabilities (aged 30-70 years), including intellectual disabilities, residing in the New England region. The second was a sample of 11 adults who had roles as the primary contact person for a family member, with a lifelong disability. All were aged 50 years or older.

The researchers undertook several steps before the data collection phase to enable potential participants to give consent freely. To allow for informed consent amongst the first group of participants, the sample was limited to people whose intellectual disability was categorised as 'mild' based on the definition used under the International Classification of Functioning, Disability and Health.<sup>12</sup> Therefore all participants were able to give informed consent to being part of the study. The relevant Human Research Ethics Committee of the university approved the project. Initial contact with participants was made via local disability service agencies. We provided designated staff from each of the local agencies with information packages for distribution to potential participants. These contained a detailed plain language description of the project, along with an invitation to contact the researchers if the participant was interested in more information. Participants were asked to communicate their agreement to be interviewed to their respective disability service agency. They had the right to refuse to be involved or withdraw consent at any stage of the project, without affecting the availability of services by their disability agency. Contact details for participants willing to take part in the study were forwarded to the researchers by the disability agency staff. The researchers then directly contacted potential participants to set up a time and venue of their choosing for the interview.

The participants' agreement to the interview was reconfirmed at the time of the interview both verbally and in writing. All participants, except one, agreed to the interview being taped. At the interview a duplicate copy of the plain language information sheet (outlining the study details and information on counselling support), as well a signed copy of the consent form was provided to each participant. A letter of thanks was sent to each of the participants at the conclusion of the data collection phase.

Through a largely unstructured conversation style interview process we recorded stories of people's past and current experiences of living with a disability as it impacted on their health, accommodation, employment and leisure activities. Similar interviewing techniques were used to explore and record the stories of family members. Most interviews were conducted with individuals in their own home, with

several couples participating in joint discussions. With the benefit of hindsight, different and possibly more detailed information may have been forthcoming if separate times had been allocated to each partner.<sup>13</sup>

The interviews were transcribed verbatim and pseudonyms were allocated to each participant. The process of analysis involved review of sections or passages within the context of the entire interview to identify the major themes. These themes were identified from the transcripts and drawn together to develop an understanding of the perspectives of each group, with particular focus on the similarities and differences both within individual narratives and across the interview data.<sup>14,15</sup> The questions were modified as the interviews progressed to build on the stories that emerged.

Approximately half of the participants with a lifelong disability had been born and always lived in the rural town where they were interviewed. Other participants had lived in various parts of New South Wales, but were now settled and had or were expected to retire in their current rural town. Most of those people who lived away from the family home maintained some ongoing contact with family members. Although we did not explicitly set out to select and interview dyads of individuals with disabilities and their family members, over half of the participants in the study were related.

## Results and discussion

### Health issues for individuals with disabilities

Just over a decade ago it was asserted: 'Most Australian adults can be responsible for their own health, but we can rarely expect this of people with an intellectual disability'.<sup>16</sup> In more recent times, it has been suggested that this population 'have a high rate of unmet health needs'.<sup>10</sup> However, most of the participants with a lifelong disability interviewed in this study, demonstrated an awareness of their health status and discussed how they actively managed health issues or were supported to do so by service providers and/or family members. Many reported having checkups twice a year, using specialist services when required, as reflected in the following:

*Freid:* I'm getting a bit of arthritis ... that sometimes gets me in the neck ... I have regular check ups ... six months ... just like to do a check in sometimes.

*Alex:* Only when I get the appointment made for me ... the staff makes the appointment for me, twice a year.

The levels of awareness of health and well-being issues can, at least in part, be attributed to the development and implementation of the Intellectual/Developmental Disabilities Health Checklist as a cross-agency health assessment tool. The New England Division of General Practice in collaboration with Challenge Armidale (a local disability organisation) supported the development of this checklist. The associated VET Tool Kit provided appropriate training and assessment skills along with nationally recognised qualifications for staff working in disability services. The VET Tool Kit was specifically aimed at enabling workers 'to play an active role in facilitating the flow of communication between the service users, the medical practitioners and other health professionals'.<sup>17</sup>

Delays in accessing orthopaedic and dental services were noted by the participants and/or their carers. Such delays were common place, as reflected in the comments of the following participant, Robyn: *Actually, he's got to go to the dentist next Thursday ... the community one. He's been waiting oh, for twelve months [to] eighteen months I s'pose.* Many of the carers themselves had age-associated health problems, some requiring significant medical intervention. A few of the participants commented on the impact of ageing on their general practitioner and the strategies they had put in place to respond to this problem, such as Jedha: *I reckon he's getting too old. Reckon he's getting ready for retirement ... Have a look around for another one.*

Availability of an adequate medical workforce, including General Practitioners (GP), is an issue in many rural and regional areas of Australia. There is also an acute shortage of dental care in the public health care system in rural areas. Population-based study of adults with intellectual disability found dental problems to be the most common health issues as reported by 86% of the samples.<sup>18,19</sup> A national survey of GP attitudes and provision of health care found that only 14% undertook or facilitated dental care for their clients with disability.<sup>20,21</sup>

### Issues for family members

Ageing and health issues have an impact on family members ability to be direct carers. In several recent studies parents identified concerns surrounding their own resilience and ability to provide ongoing support to their family members.<sup>10,11</sup> In our study several people talked of the challenges of preparing themselves and their family member for separation. One mother described the difficulty she had in taking proactive steps to facilitate her daughter to live away from the family.

*Laura:* Our lives—until she left, centred around her, and when it, when it came to the stage when she first left home, I was dead against it, because I thought she—I really believed that she couldn't cope. I underestimated her and I believe that's what mothers generally do. And I dunno, I made the silly statement, "Over my dead body", when they said it, and one of my daughters said very sensibly: "Yes Mum, that's what it will be! Not only will she have to cope with your death, but she's gonna have to cope with—for the first time in her life, being entirely dependent, too—independent, I mean, too." And, so I woke up—but I might tell you, I didn't sleep very well the first couple of weeks when she was away.

Making the break at this time was a difficult, but ultimately an enabling step for all concerned. Although they no longer live together, Laura remains in regular contact and maintains an active role in oversight of her daughter's health and well being.

*Laura:* I still prefer ... to take her to the doctor, or dentist, or—she makes her own appointments, for whatever needs doing—and I usually go with her—they [the service organisation] would, if it was necessary.

Laura continued to engage in this way, but was also conscious that the service organisation was willing and available to provide backup, if she was not longer able or available to be involved. Several parents expressed concern that if their family member moved out of home to live on their own, they both would be lonely. Independent units within a village complex with support available, was suggested as a viable option by a family carer. Although parents continued to play a role in the lives of their adult offspring, they were not always able to provide direct support.

Service providers may automatically assume that all parents want to remain the primary carer for their family member or alternately that the person with a lifelong disability wants to stay in the family home. However it is important to heed a recent warning for the need to be aware that 'family dynamics are not necessarily health-promoting'.<sup>8</sup> For one of the parents in this study who was experiencing a chronic illness, provision of supported accommodation for his daughter was a vital aspect of maintaining family well being.

*Harry:* That's the whole trouble, if we had Alison, if we had Alison now it would just be impossible! This [supported accommodation for her] is the best thing that ever happened to us.

Community residential living for adults with lifelong disabilities has been a relatively recent experience and one that some service agencies are still grappling with.<sup>22</sup> In rural NSW, long distances between towns and communities, plus inadequate provision of public transport pose significant problems in maintaining family support networks, especially as parents age and siblings move out of the area for employment purposes.<sup>23</sup> For some individuals and their families, out of area placements while necessary from a service

provision point of view, can dilute and over time limit the degree to which family can be engaged in the social support network.<sup>24</sup> Studies have found that family contact declines with distance.<sup>25</sup> Equally social isolation is a major concern for the overall well being of older adults with intellectual disability,<sup>26</sup> particularly those with dual diagnoses. In our study regional residential arrangements varied, but generally included historical reasons such as lack of appropriate options and/or availability of local services.

*Harry:* ... they were calling me out in the middle of the night. It's a long drive from here to Tamworth! Oh, they called from Newcastle too. Tamworth said they couldn't handle it, so they sent her from Tamworth to Newcastle. And, um, they rang us up at twelve o'clock at night and said that if we didn't come and get her straight away, they'd put her on a bus and she had no slippers, no nothing. On the train, on the train...[to] Morisset. Yes, they reckoned she wasn't good enough there. The whole trouble is, Alison is between the two. She's not bad and she's not good. She's between the two and you put her in one and, righto, she's too good for here. We'll her put over here. Oh no, she's too good for here. She's between the two. We had her everywhere ... And there's not only Alison in that case, we found out there's lots of other people ... Nowhere for them to go. And, anyhow all those [changes are] finished now [for -Alison].

### Social support networks and retirement planning

Studies of people with disabilities, have shown that social support networks vary from person to person, as well as across regions.<sup>27</sup> In our study participants with a disability reported small, but active social network. Most indicated that they enjoyed regular attendance at activities organised at social clubs within the community. They would eat out or go to concerts at these venues, plus participate in dances, raffles, bingo and similar activities. In many instances, the transport for such social events was provided or facilitated by the local disability service agencies. For many participants who had a family member/parent living in another town, regular contact was maintained by telephone and through visiting. The frequency of such visit varied by geographic distance and closeness of emotional bonds between the individual and their family.

It has also been acknowledged that retirement planning is complex and multifaceted for people with disabilities.<sup>28</sup> It has been suggested that a very small proportion of older adults with intellectual disabilities and their family members had planned for retirement.<sup>4</sup> This has occurred despite the increasing recognition of the appropriateness of person-centred care for all stages of life.<sup>29</sup> In our study a number of the participants and parents had already retired. Other participants with disabilities continued to work and were close to or past the formal employment retirement age. It was evident that some thought had been given by many of the participants to the impact of retirement on their daily life, for example:

*Penny:* I'm just getting too tired ... I'm gonna be retired one day —about another two years ... I'm going to relax [laughs]. I'm not going to get bored. Sort of relax, then a little bit of craft or something ... I'll get up and water the garden every second day.

However, not everyone had a clear understanding of the implications of retirement. Some participants had vague plans in mind about what the future held for them, such as relocating their place of residence.

*Fran:* Oh well, I'm 50 ... I dunno [when I'll retire], about 60 or something. I don't know [what I'll do]. I'm hoping I'm gonna live somewhere else ... a little closer to town.

Some of the participants who had retired looked forward to linking up with friends who they had previously worked with.

*Stephanie:* Yeah, we often get together [at the club] ... Not all the time. Only, only on ... when it's birthdays, or we just go out watching a concert ... well, we don't go down there all the time—not during the winter, anyway ... too cold at night! Rather be rugged up in bed ... and watching TV.

Such social connectedness was not the reality for all families or individuals in this study. As pointed out by one of the study participant, a mother of a young adult with lifelong disability: *they don't really connect with each other. They're little isolated modules and everybody rotates around them ... Their connection with the world is very limited.* The availability of meaningful leisure activities was problematic in small rural communities, with limited options for retired older adults in general and those with lifelong disabilities in particular. Some parents also identified concerns about engaging their family member in meaningful activities, over and above purely recreational pursuits.

*Mary:* So, the problem is, what do they do for the rest of their lives ... if you're not, you're not able to plan a career for yourself or a job, or do something or other, or what you are doing is, is doing all these activities [with your child].

## Conclusions

Tapping into the subjective views of ageing peoples with disabilities and their families revealed how the rural context in which they lived influenced the health and social well being of everyone involved. In general terms the data from this study affirms the claim 'that supports and resources in one's surrounding environment'<sup>5</sup> influence the activities that people with lifelong disabilities engage in. Friends, families and service agency staff all play roles in shaping day-to-day encounters. There are a number of policy and programmatic recommendations emanating from the present study. Whilst the present study showed satisfaction with access to general practitioners for people with lifelong disabilities, the access is not universal across all rural towns in northern NSW. Access to public dental care remains an issue for all rural residents and is particularly an issue for people with lifelong disabilities who tend to have poor dental health both due to disability and limited availability and access to public dental services.

Beyond health concerns, one of the most salient concerns voiced by adults with lifelong disabilities and their family members was the availability of supported accommodation within the rural towns in which people with disabilities and/or their family members currently reside. The availability of appropriate supported accommodation in rural towns will enable smooth transition to retirement and ageing in place, concepts that are as important for older people with lifelong disabilities as for those without such disability. Integrated supported accommodation services will enable continuation of social networks, which though limited for people with disabilities in rural areas, are absolutely essential for their sense of social and emotional well being and to minimise their further social isolation and marginalisation.

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## References

1. Bittles AH, Petterson BA, Sullivan SG, Hussain R, Glasson EJ. & Montgomery PD The influence of intellectual disability on life expectancy. *J Gerontol A Biol Sci Med Sci* 2002; 57: 470-472.
2. Factor AR, Aging with a developmental disability. White House conference on aging. Listening session testimony. 2004 [www.whcoa.gov/about/policy/meetings/summary/factortestimony.pdf](http://www.whcoa.gov/about/policy/meetings/summary/factortestimony.pdf), accessed on 26 June 2006.
3. Owen L, Gordon M, Fredrico M, & Cooper B, Listen to us. Supporting Families with Disabilities: Identifying Service Responses that Impact on the Risk of Family Breakdown. School of Social Work and Social Policy, La Trobe University, Melbourne, 2002.

4. Bigby C, Ageing people with a lifelong disability: challenges for the aged care and disability sectors. *J Intellect Dev Disabil* 2000; 27: 231-241.
5. Clarke P & Black SE, Quality of life following stroke: Negotiating disability, identity, and resources. *J Appl Gerontol* 2005; 24:319-336.
6. Dyches TT, Cichella E, Olsen SF & Mandelco B, Snapshots of life: Perspectives of school-aged individuals with developmental disabilities. *Research and Practice for Persons with Severe Disabilities* 2004; 28:172-182.
7. Hughes V, Civil society and markets in disability and mental health, *Interactions* 2006; 19:7-23.
8. Huntir A, Institutions, popularism and the practice of community support. *Interactions* 2006; 19:31-35.
9. Clegg J, Sheard C, Cahill J & Osbeck L, Severe intellectual disability and transition to adulthood. *Br J Med Psychol* 2001; 74:151-166.
10. Bigby C, Ageing with a lifelong disability. A guide to practice, program and policy issues for human service professionals, Jessica Kingsley, London, 2006.
11. Llewellyn G, Gething L, Kendig H & Cant R, Older parent caregivers' engagement with the service system, *Am J Ment Retard* 2004; 109:379-396.
12. WHO, International Classification of Functioning, Disability and Health (ICF). World Health Organization, Geneva, 2001.
13. Maple M, Plummer D, Edwards H & Minichiello V, The effects of preparedness for suicide following the death of a young adult child, *Suicide Life Threat Behav* 2007; 37:127-134.
14. Polkinghorne D, Narrative configuration in qualitative analysis. *Qualitative Studies in Education* 1995; 8:5-23.
15. Reissman CK, Narrative methods for the human sciences, Sage, Los Angeles, 2008.
16. Beange H, Caring for vulnerable population: Who will take responsibility for those getting a raw deal from the health care system? *Med J Aust* 1996; 164: 159-160.
17. Directions Australia, VET tool kit to support training and assessment in the health and wellbeing of people with disabilities, Directions (Australia), Maleny, 2005.
18. Beange H, McElduff A & Baker W, Medical disorders of adults with mental retardation: a population study. *Am J Ment Retard*, 1995; 99:595-604.
19. Scott A, Marsh L & Stokes ML, A survey of oral health in a population of adults with developmental disability: comparison with a national oral health survey of the general population. *Aust Dent J* 1998; 43:257-261.
20. Lennox NG, Beange H & Edwards NS, The health needs of people with intellectual disability. *Med J Aust* 2000a; 173:328-30.
21. Lennox NG, Diggins J & Ugoni A, Healthcare for people with an intellectual disability: General practitioners attitudes and provision of care. *J Intellect Dev Disabil* 2000b; 25:127-133.
22. Jokinen NS, Older adults with intellectual disability living in a community residential service. *International Journal of Disability, Community & Rehabilitation* 2003; 2 [http://www.ijdc.ca/VOL02\\_01\\_CAN/articles/jokinen.shtml](http://www.ijdc.ca/VOL02_01_CAN/articles/jokinen.shtml)> accessed 18 September 2007.
23. Parmenter G, The social interactions of people living in nursing homes in a rural setting. Unpublished PhD thesis. University of New England, Armidale, 2006.
24. Beadle-Brown J, Mansell J, Whelton B, Hutchison A & Skidmore C, Too far to go: Out of area placements for people with intellectual disabilities. *Tizard Learning Disability Review* 2006; 11:24-34.
25. Walsh PN, Lincoln C, Hillary J, Durkan J, Emerson E, Hatton C, Robertson J, et al. Family view of the quality of residential supports. *J Appl Res Intellect Disabil* 2001; 14:292-309.
26. Janicki MP, Dalton AJ, Henderso, CM & Davidson PW, Mortality and morbidity among older adults with intellectual disability: Health services considerations. *Disabil Rehabil* 1999; 21:284-294.
27. Mahon M & Mactavich J, A sense of belonging—older adults perspectives in social integration. In M.P. Janicki & E.F. Ansello (eds) *Community Supports for Ageing Adults with Lifelong Disabilities*, Paul Brooks, Baltimore, 2000; 41-53.
28. Hodges JS, Luken K & Hubbard A, Supporting the transition of one man with autism from work to retirement. *Ther Recreation J* 2004; 38:301-311.
29. Schalock RL, Brown I, Brown R, Cummins RA, Felce D, Matikka L, et al. Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Ment Retard* 2002; 40:457-470.

## Presenter

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