



**Life Without Barriers Submission - PLANNING OPTIONS
AND SERVICES FOR PEOPLE AGEING WITH A DISABILITY**

Life Without Barriers

**Submission to the Senate Community
Affairs References Committee Inquiry
into Planning Options and Services
for People Ageing with a Disability**

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1.0 Executive Summary

This submission for the inquiry into planning options and services for people ageing with a disability explores issues raised by Life Without Barriers, a non government provider of disability services, and in particular staff members Pam Alley and Sharon Armanski who work with and plan services for people ageing with a disability.

A range of issues are raised in the submission including the fact that many older parent carers do not utilise services that are available such as day programs and respite because they do not know about them or do not trust them leading to a recommendation to work more with parent carers to make them aware and to allow them to trust the services that are available to them to support their child with a disability.

Another issue raised in this submission is when older parent carers are no longer able to take care of their loved ones. For example when older parent carers lose mobility, this can impact on the quality of life of their adult son or daughter as they can no longer take them to regular services such as day programs. Also upon the death of older parent carers, a lack of planning means their children with disabilities are often abruptly transferred to supported accommodation which can cause a range of problems for the person with a disability and those supporting them. A recommendation to improve this transition is to support parent carers to plan for the future of their loved one, and such plans may include the identification of a key person to make the transition between home and accommodation easier.

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A further issue identified is that when people ageing with a disability have to abruptly cease employment and go into retirement. This causes a range of problems as many people with a disability do not have the finance or capabilities to undertake activities after they finish employment. Recommendations towards this include educating people with a disability about retiring and planning around the range of options that are available afterwards, and providing more funding to support service providers to make services such as day programs more affordable for their clients.

Another issue raised in this submission is that of people ageing with a disability being transferred to nursing homes due to increased support needs which can be detrimental to their physical and mental health because for example nursing home staff are not generally trained to work with people with disabilities and many of the people who are transferred are suddenly cut off from services such as day programs and also friendships. One recommendation to address this situation is the need for continued practical support to be provided to clients who have been transferred to aged care facilities to enable them to continue using services, such as by providing transport.

The final issue raised in this report is that people with a disability do not often receive appropriate health care due to what seems to be a lack of integrated service delivery between the disability and healthcare sectors therefore there needs to be better planning for the health care of people ageing with a disability.

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2.0 Introduction

This submission aims to demonstrate the views of Life Without Barriers on the issues of planning options and services for people aging with a disability. After providing a brief background of Life Without Barriers and why they are making this submission, the report will then discuss several issues which fall under the categories of people ageing with a disability living with older parent carers, when older parent carers can no longer support their loved one, the change from employment to retirement for people ageing with a disability and also people with a disability being transferred to residential aged care. The report will also make various recommendations in response to the issues raised.

3.0 Background

Life Without Barriers is a not for profit organisation which has locations across Australia and New Zealand and which is committed to providing a supportive and safe environment for people living with a disability or mental health issue, children and young people and other vulnerable persons. Life Without Barriers aims to provide quality support services for people aging with a disability through approaches such as promoting and supporting positive relationships, adapting to people's changing needs, strengthening families, enhancing decision making and focusing on health. Support services provided by Life Without Barriers include in-home / community living support services, attendant care services, alternative family care arrangements, supported accommodation and a flexible range of respite service options.

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Because of their work with people ageing with a disability, the staff at Life Without Barriers understand their clients' needs and are able to provide insight into what may be done to improve their quality of life and future. Therefore Life Without Barriers is submitting this report for the inquiry into planning options and services for people ageing with a disability, with hopes to put forward valuable insight about this situation in order to help their clients, ensure their continued quality of life as they and their carers age, and to identify inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers.

The two Life Without Barriers staff who were interviewed and whose views are represented in this submission are Pam Alley, the Support Coordinator for Life Without Barriers Older Parent Carer Program in the New England region and Sharon Armanski, Manager of Life Without Barriers Disability Day Programs in the Hunter Region. These two women not only work with people ageing with a disability but are also responsible for coordinating programs and services for these clients. Secondary research was also conducted for this submission to support issues raised by Pam and Sharon with academic research.

Issues surrounding the planning options and services for people ageing with a disability that were raised by Pam Alley and Sharon Armanski, and which are elaborated on below, include:

- older parent carers not utilising services for their son or daughter with a disability because they do know about them or do not trust them,
- a lack of services in rural areas,

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- reduced mobility of older parent carers affecting the lives of people ageing with a disability,
- the transition for a person ageing with a disability from the family home to supported accommodation when their parents pass away or are otherwise no longer able to support their child and the necessity for carers to plan for incidences such as this including the advantages of involving a key person to make this transition easier,
- the transition from employment to retirement for people ageing with a disability, the need to prepare them for such incidences, and also the need for them to continue doing things after retirement, and finally
- people ageing with a disability being transferred to nursing homes and the problems this causes as well as the need for them to get access to appropriate health care and to continue their friendships.

4.0 People ageing with a disability living with older parent carers

The issue of people ageing with a disability living with older parent carers is an important one because many of the parent carers do not utilise services that are available, such as day programs or respite for their adult son or daughter. Pam Alley identified that this issue is worse in rural areas where there is a lack of support services as well as a lack of knowledge about the amount of people with disabilities that live in such areas because the families have never sought support.

Bigby, Fyffe and Ozanne (2007, p. 216) write that “for many of the current generation of middle-aged people with intellectual disabilities who remained living

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at home with parents, care and support have been largely private family responsibilities.” Almost half of the families who are caring for an aging person with a disability are not using formal services. Reasons for this include parents not knowing about the services that are available, feeling as though they do not need or cannot trust such services, or fearing that the services will separate the family (Bigby, Fyffe & Ozanne 2007).

Bigby, Fyffe and Ozanne (2007, p. 218) also point out that because of the reasons above, “adults living with elderly parents may have had few opportunities to develop a separate life, and in some cases they may never have spent a night away from home.” Therefore, support service providers should be working more with older parents, especially in rural areas, to make them aware of the services available or to gain their trust in the services to help themselves and their adult son or daughter (Bigby, Fyffe & Ozanne 2007).

5.0 When older parent carers can no longer support their loved one

Another issue raised is that “the reduced mobility of parents...and support of their adult child can restrict the lifestyle of the adult, who may have been reliant on their parents for social outings. The inability of parents to meet inflexible pick-up times or full-time attendance requirements of day programs may lead to some adults dropping out, thus further restricting their lifestyle” (Bigby, Fyffe & Ozanne 2007, p. 18).

Pam Alley also raises the issue of when older parent carers pass away. If the parents did not establish a plan for their son or daughter with a disability, then

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this person is usually transferred into supported accommodation and the situation is often “exacerbated by the shortage of accommodation support in disability services” (Bigby, Fyffe & Ozanne 2007, p. 18).

Pam says that the sudden transfer for a person with a disability, from their family home to supported accommodation, can cause high levels of stress and impacts on mental health including such issues as anxiety and even early onset dementia. Hazel Morgan, Head of the UK Foundation for People with Learning Disabilities, also discusses this matter and says that one part of the solution is to identify older family carers in the community and ensure that they have a plan so that their child’s needs are met in the future (Planning for Tomorrow 2003). Pam Alley reiterates that it is important to prepare people with disabilities for such instances so as to avoid mental health issues when they happen.

Bigby, Fyffe and Ozanne (2007, p. 220) also suggest that older parent carers make informal plans “whereby a key person is identified to oversee the adult’s wellbeing and negotiate access to support rather than provide hands-on care.” This key person, who the adult with a disability knows, makes the transition from the family home to supported accommodation much easier, and the key person is also able to see what the individual wants and how they are feeling. Also “by mandating the intervention of a key person...these plans relieve parents from confronting the challenges of making detailed transition arrangements that may involve difficult choices and conflicting values and needs” (Bigby, Fyffe & Ozanne 2007, p. 220).

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6.0 The change from employment to retirement for people ageing with a disability

Sharon Armanski and Pam Alley both talk about the issue of retirement for people ageing with a disability. First of all, when people with a disability retire, it is not planned like most people but is often an abrupt process and something which they are not prepared for. Bigby and Grant (2003, p. 133) write that “older people with disabilities who are working seldom express the desire to retire and are concerned about loss of income and social isolation if they cease working.”

However, because people with disabilities may have little choice in whether they retire or not, there needs to be a better transition process in place for when they do. Bigby, Fyffe and Ozanne (2007) indicate that a solution to the abrupt change in lifestyle from employment to retirement for people with a disability is support and education groups to enable them “to explore aspects of ageing and associated social expectations” in order to better prepare them for the future. Examples of this which are effective are pre retirement group programs (Bigby, Fyffe & Ozanne 2007).

Sharon Armanski also points out that many people with disabilities do not have the finances, abilities or resources to independently engage in the usual retirement pursuits of travelling or engaging in various hobbies during their retirement years resulting in reduced activity, boredom and social isolation. Bigby and Grant (2003, p. 133) point out that “older people with intellectual disabilities experience few opportunities to participate in meaningful day and leisure activities of their choice.” This is why it is not only vital to make people with disabilities aware of funded services which exist for them after retirement,

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tailor them to suit client preferences, make them more age appropriate and widely available and more affordable for clients - all of which will require more funding.

7.0 People with a disability being transferred to residential aged care

A key issue identified for people ageing with a disability is that they are often transferred to a residential aged care facility (i.e. a nursing home). This may take place if service workers believe the client needs more intensive medical care, but unfortunately “evidence also suggests older people with intellectual disabilities may be ‘misplaced and forgotten’ in residential aged care (Thompson and Wright 2001, cited in Bigby, Fyffe & Ozanne 2007, p. 227). Sharon states that this can be detrimental to the client’s physical and mental health in many different ways.

First of all, many of the nursing homes which clients are transferred to do not have staff that are trained in caring for a person with a disability, therefore the clients may not receive the proper care and support they need. This is supported by evidence which suggests that “staff in disability services have limited knowledge about ageing processes, and staff in the healthcare and aged-care sectors have little knowledge about people with intellectual disabilities” (Bigby, Fyffe & Ozanne 2007, p. 227).

Such inappropriate placements stem from the lack of policy in relation to people ageing with a disability and “unresolved debates about the stage at which...a person with a lifelong disability simply becomes an older person and which service system – disability or aged care – should be responsible for supporting

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the person” (Bigby, Fyffe & Ozanne 2007, p. 227). However, rather than seeing the problem as one system or another, it should be more a case of considering what possibilities the different systems offer, for example disability care, aged care, and health care. For a person ageing with a disability, such different services will be relevant at different times in their life.

People with intellectual disabilities are also disadvantaged in terms of accessing good quality healthcare. “This suggests that ensuring regular timely access to quality health services should be central to case management with older people” and also suggests that a stronger relationship between disability and health care sectors would be advantageous for people aging with a disability (Bigby, Fyffe & Ozanne 2007, p. 228).

Sharon Armanski also says that after being transferred to a nursing home, many of her clients no longer attend day programs due to reasons such as transport, cost or not being aware that they are allowed to leave the nursing home. A study by Canrinus and Lunsky (2003), in which several women in their late forties or older with intellectual disabilities were interviewed, reveals similar issues in that most women struggled financially and relied on the government for economic support, and therefore due to lack of finances they could not do the activities they wanted to do. This again raises the need for more funding for services such as day programs to make them more affordable for clients.

Day programs, such as those provided by Life Without Barriers, allow clients to see friends, participate in activities, go on trips and even to passively enjoy the company of others. Any abrupt discontinuation of this routine can severely affect

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a client's mental health and while friendship is a valued social role, it is often neglected in situations such as these. Evidence suggests that friendships between people with intellectual disabilities "should not be overlooked, as they can have depth, richness and longevity and be central to a person's sense of significance and belonging" (Bigby, Fyffe & Ozanne 2007, p. 225). A solution to clients no longer attending day programs because they have been moved to an aged care facility would be to stay in contact with them and offer them ways to maintain their placement in their funded day program placement (e.g. by providing transport).

8.0 Conclusion

This submission has attempted to outline a number of the views of Life Without Barriers staff on the issues of planning options and services for people aging with a disability. These views, supported through the literature, involved the key transition points and stress areas of people ageing with a disability living with older parent carers, when older parents carers can no longer support their loved one, the change from employment to retirement for people ageing with a disability and also people ageing with a disability being transferred to residential aged care. The following recommendations are made by Life Without Barriers for the consideration of the Senate Community Affairs References Committee in order to stimulate thought on possible options to improve the quality of life of Australians who are ageing with a disability.

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9.0 Recommendations

9.1. In relation to people ageing with a disability living with older parents carers, it is recommended that every effort is put toward identifying families who live with a person with a disability. Once identified, older parent carers should be contacted in order to develop linkages with the service system, identify the support needs of their son or daughter and to educate them about funded services that are available, or to gain their trust in the services. This is particularly vital in rural areas where families may be isolated, and these areas should also be investigated as they are frequently in need of more support services.

9.2. Older parents carers should be informed, educated and provided with resources and tools and the support to use them to assist them with planning for the future of their loved one and educated on options such as involving a key person so that when they pass away or are no longer able to support their son or daughter, it is an easier transition for them to move to supported accommodation.

9.3. In terms of the change from employment to retirement for people ageing with a disability, more educational material and programs should be developed and made available to support people with a disability to learn about retirement, ageing and associated social expectations. Also, the day programs and activities available for people ageing with a disability need to be assessed and where necessary changed to suit client needs, more funding provided to make them more affordable for clients, and other options investigated for people ageing with a disability for when they retire, such as holiday planning and funding.

9.4. People ageing with a disability who are transferred to residential aged care need to be assessed to see if they require further lifestyle support such as transport to day programs or even a casual carer (e.g. to engage in community

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access and participation activities). Once again, more funding is needed to make day programs more affordable for clients.

9.5. The health of people ageing with a disability should be better supported through enhanced primary care services and ensuring an integrated approach to support so that people ageing with a disability have access to the health support they need including both generic and specialist health support services.

10.0 References

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