Office of the Public Advocate

Ageing Well: Supporting Better Quality of Life for People with Disabilities

Submission to the Inquiry into Planning Options and Services for People Ageing with a Disability

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Contact: John Chesterman
Manager, Policy and Education
Office of the Public Advocate

Prepared by: Magdalena McGuire
Legal Policy & Research Officer
Office of the Public Advocate

Office of the Public Advocate
Level 5, 436 Lonsdale Street, Melbourne, Victoria 3000
PO Box 13175 Law Courts, Victoria 8010. DX 210293
Tel: 1300 309 337 Fax: 1300 787 510
www.publicadvocate.vic.gov.au

Contents

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Glossary of Acronyms and Abbreviations

DHS	Department of Human Services
Inquiry	Inquiry into Planning Options and Services for People Ageing with a Disability
OPA	Office of the Public Advocate

1. About the Office of the Public Advocate

1.1 The Office of the Public Advocate (OPA) is a statutory office, independent of government and government services, that works to protect and promote the rights, interests and dignity of people with disabilities. OPA provides a number of services to work towards these goals, including the provision of advocacy, investigation and guardianship services to people with a cognitive disability. In the last financial year, OPA's Advocate/Guardians provided guardianship services in 1334 cases and temporary guardianship in 60 cases. Dementia (34%) was the most frequent disability type among guardianship clients, followed by mental illness (17%), acquired brain injury (16%) and intellectual disability (14%).[1] Many of OPA's clients have more than one disability (such as an intellectual disability and dementia, for example). OPA's clients tend to have complex needs arising from their disabilities and other circumstances such as age and cultural and linguistic backgrounds.

1.2 Another significant function of OPA is its oversight of the Community Visitors program. Community Visitors are volunteers who are trained by OPA and who are empowered by law to visit Victorian accommodation facilities for people with a disability at any time, unannounced. Community Visitors are authorised to visit community residential units (managed by the Victorian Department of Human Services (DHS)), supported residential services (privately run services), and mental health facilities. They monitor and report on the adequacy of services provided to residents and patients, including those who are ageing with a disability. In the last financial year, OPA coordinated the work of over 500 volunteer Community Visitors, who conducted 5,413 visits to a range of accommodation settings in which people with disabilities reside.[2]

1.3 This work gives OPA a unique perspective on disability and ageing. OPA therefore welcomes the opportunity to provide input to the Inquiry into Planning Options and Services for People Ageing with a Disability (the Inquiry). This submission highlights some of the key areas of concern regarding disability and ageing that have been brought to OPA's attention through its advocacy, investigation and guardianship work. This submission does not seek to give a comprehensive analysis of the aged care and disability sectors as a whole. Rather, it confines itself to addressing the particular topics about which OPA can speak with authority and insight.

[1] OPA, *Annual Report 2008/09*, pp. 8-9 available at http://www.publicadvocate.vic.gov.au/file/file/Report/OPA%20Annual%20Report%202009/OPAAnnualReport0809_121009Compressed.pdf?phpMyAdmin=fe8bb73b8ddef429ba268102bddcf16c.

[2] OPA, *Annual Report 2008/09*, p. 46; OPA, *Community Visitors Annual Report 2009*, p. 10 available at http://www.publicadvocate.vic.gov.au/file/file/Report/CommunityVisitors_AnnualRep%202009_Web.pdf.

2. Summary of Recommendations

2.1 This submission makes the following recommendations:

RECOMMENDATIONS

1. That better cross-sector coordination be developed between the aged care and disability sectors in order to facilitate the effective delivery of services to people with disabilities.

2. That the government develop and resource more flexible, creative accommodation and support options for people with disabilities throughout their lifespan.

3. That a more nuanced, holistic approach is undertaken to the policy of 'ageing in place'. This approach must prioritise the right of people with disabilities to enjoy as high a quality of life as possible at home, at work and in the community.

4. That the healthcare and disability sectors develop and implement policies that address the difficulties experienced by people with disabilities in accessing optimal healthcare.

5. That the government address the shortfall in the numbers of permanent and respite accommodation places.

6. That a national review be undertaken of the population characteristics and support needs of Australians ageing with disabilities and their carers.

7. That the aged care and disability sectors develop and implement protocols for enabling people ageing with disabilities to make effective accommodation and care transitions. These protocols should include measures for improving the health and wellbeing of people with disabilities, including the provision of services such as grief counselling and case management where necessary.

3. Age vs Disability?

3.1 One of the key factors that hinders the effective delivery of services to many people ageing with a disability is the rigid boundary between the aged care and disability sectors. In OPA's experience, there is insufficient collaboration between the aged care sector (which is managed by a combination of Commonwealth, State and Territory services) and the disability sector (which, in Victoria, is primarily managed by DHS). This lack of collaboration can create significant gaps in service delivery for people ageing with a disability. The result is that many such people face a 'double disadvantage' by virtue of their age and disability. As one OPA staff member put it: "the age stuff is frightening to DHS and the disability stuff is frightening to aged care".

3.2 This problem is particularly acute within residential services. For example, several of OPA's Advocate/Guardians have reported difficulties in finding suitable accommodation options for older people with disabilities. These Advocate/Guardians have found that, while aged care facilities are accustomed to supporting residents whose needs are changing as a result of older age, they can be reluctant to accept older people with 'lifelong' or 'pre-existing' disabilities such as an intellectual disability or a mental illness.[3] According to these Advocate/Guardians, many staff at aged care facilities appear to feel "out of their depth" with disability; likewise they seem to perceive people with disabilities as having needs that are "too complex" for the aged care sector.

3.3 At the same time, disability accommodation facilities can be ill equipped to meet the changing needs of their ageing residents. For example, many of OPA's Community Visitors have reported that there are people with disabilities ageing in supported residential services whose complex needs are not being met. Some of these people, Community Visitors believe, would be more appropriately placed in aged care facilities. Some OPA staff members have also expressed concerns that, as supported residential services are privately run, they can have a strong financial incentive for keeping on residents for longer than is appropriate. This difficulty is compounded by the fact that DHS regards supported residential services as a 'home-like environment' and, therefore, favours a non-interventionist approach to this sector. This has resulted in a lack of accountability in the way that supported residential services approach the needs of their ageing residents.

3.4 Several of OPA's Advocate /Guardians have also spoken of the difficulties that can arise when a resident in a community residential unit develops an age-related medical condition and needs

[3] For the purposes of this submission, the term 'lifelong' disability is used to refer to people who have lived most of their lives with a developmental or other disability. The term 'pre-existing' disability is used to refer to people who have acquired a disability before reaching older age. See Fyffe, C., Bigby, C. and McCubbery, J. 2006 *Exploration of the Population of People with Disabilities Who Are Ageing, Their Changing Needs and the Capacity of the Disability and Aged Care Sectors to Support Them to Age Positively*, National Disability Administrators, Short Report: Key Findings, p.1.

a higher level of care. In their experience, the view of DHS tends to be that such a person would be 'better off' in an aged care facility. This view does not adequately account for the diverse needs of people ageing with disabilities. For some people, the transition into aged care may well be appropriate. However, for others, the move may be one that privileges their physical care needs at the cost of their – equally important – social and personal needs.

3.5 The balance between physical care, social and personal needs, is one that is particularly pertinent to young people with disabilities. In OPA's experience, young people with complex and severe disabilities are often placed in aged care facilities simply because there is nowhere else for them to go.[4] OPA strongly believes that the placement of young people in aged care facilities significantly limits their quality of life. Young people living in aged care facilities can experience extreme isolation, a reduced sense of self worth, and even ill health as a result of inappropriate accommodation and care. This concern highlights the fact that planning for the "continued quality of life"[5] of people with disabilities must commence well before they reach older age.

3.6 OPA emphasises that there is no one size fits all model for the provision of services to people ageing with disabilities. Currently, the aged care and disability sectors tend to deliver services in a manner that is fragmented and overly bureaucratic. In order to remedy this, effective partnerships need to be developed between the two sectors. Likewise, there needs to be greater flexibility and creativity in the way that accommodation and support services are provided to people with disabilities throughout their lifespan. On this point, OPA staff have reported that, in Victoria, there are some examples of how services can use their resources in a smarter and more strategic manner. For example, some supported accommodation services have 'up-skilled' staff so they can respond to the needs of their residents. Others have employed consultant health clinicians or disability support workers to provide specialist support to residents and staff. While these types of initiatives have worked well, the difficulty is that they have not been systematically adopted.

RECOMMENDATIONS

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2. That the government develop and resource more flexible, creative accommodation and support options for people with disabilities throughout their lifespan.

[4] The Summer Foundation reports that, in Victoria, approximately 70 people under the age of 50 are admitted to aged care facilities each year. See The Summer Foundation website, available at http://www.summerfoundation.org.au/.

[5] Senate Community Affairs Committee 2009 *Inquiry into Planning Options and Services for People Ageing with a Disability*, Terms of Reference, available at http://www.aph.gov.au/Senate/committee/clac_ctte/planning_options_people_ageing_with_disability/tor.htm.

4. Ageing in (a Decent) Place

4.1 'Ageing in place' is generally agreed to be one of the key goals of the aged care sector.[6] In broad terms, 'ageing in place' supports peoples' rights to age within familiar environments for as long as they are able. Although 'ageing in place' is a concept that is frequently evoked by service providers, it is far from straightforward. Underpinning this concept are numerous assumptions about self-determination, least restrictive environments, the value of home, and quality of life.[7]

4.2 In OPA's experience, the concept of 'ageing in place' can take on additionally complex meanings for people with disabilities. Many people with disabilities experience systemic disadvantages such as social exclusion, low levels of workforce participation and financial hardship. The challenge for the aged care sector is to adopt a policy framework for 'ageing in place' that acknowledges, and responds to, the pre-existing disadvantages faced by many people with disabilities.

4.3 In practice, the concept of 'ageing in place' can be applied unreflectively within the aged care and disability sectors. Often, the concept of 'ageing in place' is simply equated with 'not moving'.[8] This interpretation does little to ensure that people with disabilities are able to enjoy a high quality of life. Moreover, when taken too literally, this interpretation can produce absurd results. For example, one OPA employee spoke of a disability accommodation facility in which several ageing residents were no longer able to access the communal areas that were located upstairs. The response of the accommodation facility was simply to keep these residents housed downstairs and to deny them access to the upstairs facilities. The accommodation facility referred to this response as 'ageing in place'.

4.4 OPA calls for a more nuanced approach to be taken to the policy of 'ageing in place'. It is important to recognise that, in practice, 'ageing in place' will mean different things to different people. For some people with disabilities, it may mean receiving adequate support to enable them to reside in an individual home, or disability accommodation, for as long as they are able. For others, it may mean gaining access to a high quality aged care facility. In all cases, the policy of 'ageing in place' must be guided by the principle that people with disabilities are entitled to enjoy as high a quality of life as possible.

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[6] Australian Institute of Health and Welfare, *Disability and Ageing: Australian Population Patterns and Implications*, p.49.

[7] Gilson, S. & Ellen F. 1997 'When People with Pre-Existing Disabilities Age in Place: Implications for Social Work Practice' 22(4) *Health & Social Work* 290-298, p.290.

[8] Fyffe, C., Bigby, C. and McCubbery, J. *Exploration of the Population of People with Disabilities Who Are Ageing, Their Changing Needs and the Capacity of the Disability and Aged Care Sectors to Support Them to Age Positively*, p.6.

CASE STUDY – ALL SHE'S EVER KNOWN

Mary is an 84 year-old woman with an intellectual disability and dementia. She is non-verbal. Mary spent the bulk of her life living in institutions. Upon deinstitutionalisation in the 1980s, Mary was moved to a supported residential service. There were few comforts in Mary's new home. Mary lived there with 24 men and 3 women (another of whom was non-verbal).

Mary was sexually assaulted whilst living in the supported residential service. When the sexual assault was finally picked up on, OPA was appointed guardian to address Mary's accommodation issues. Mary's guardian decided that the best thing for Mary was to get her out of the supported residential service. Mary's guardian commented: "People say: why should she leave, it's her home. But the only reason it's her home is because it's all she's ever known".

Mary was assessed as requiring low-level care and she was moved to a high quality aged care facility. For Mary, this was a very positive shift. At last she was living somewhere appropriate to her care, support and personal needs.

4.5 When 'ageing in place' is understood as being about quality of life, it necessarily involves more than just where people live; it also involves how they fill their day. On this point, one OPA staff member raised concerns that many disability employment centres enforce retirement at the age of 65, regardless of their employees' wishes (this is because funding for such employees typically ceases when they reach the age of 65). Practices such as mandatory retirement can have the effect of jeopardising the relationships, sense of purpose and financial security of the person with a disability.[9] OPA strongly believes that people with a disability should be entitled to exercise the same degree of control over their retirement options as do other Australians.

4.6 Several OPA staff also cited the need for day programmes to be more flexible in their method of service delivery. Currently day programmes tend to offer people little choice in activity types or the times these activities can be undertaken. This inflexibility can prevent people with disabilities from accessing day programmes, particularly as they get older and their needs become more complex. Day programmes need to offer people a wider range of choices by, for example, restructuring some programmes from full-day to part-day activities, or by organising

[9] See for example, Bigby, C. 2009 'Aging with a Life Long Disability: Issues, Evidence and Solutions', *Ageing & Disability Forum* Oakdale Services Tasmania, 4 December 2009, available at http://www.oakdaletas.org/adforum/CBpaper.pdf.

individual arrangements that provide people with the opportunity to participate in the community and to pursue their own interests.[10]

RECOMMENDATIONS

3. That a more nuanced, holistic approach is undertaken to the policy of 'ageing in place'. This approach must prioritise the right of people with disabilities to enjoy as high a quality of life as possible at home, at work and in the community.

5. Health Promotion

5.1 People with disabilities are entitled to access healthcare services on an equal basis with all other Australians.[11] In spite of this, many people ageing with a disability continue to face numerous barriers that prevent them from accessing high quality healthcare in a timely manner. These barriers stem from limitations within the healthcare system, as well as the lack of support options available for people with disabilities. For example, one OPA volunteer described these barriers as such:

> It can be hard to find doctors who are suitably qualified and willing to take on patients with complex disabilities and age-related health issues. Once you find a suitable doctor, you face long waiting lists for appointments. When you actually get an appointment, it can be hard to arrange for a carer and transport to the appointment. As a result, people with disabilities often get only the minimum level of necessary healthcare. This isn't fair; they shouldn't be penalised for having a disability.

5.2 As people with disabilities age, their healthcare needs can become both more complex and recurrent. OPA has found that, while some health service providers are responsive to the needs of people ageing with disabilities, others are ill equipped to manage these complexities. One OPA staff member described the problem as such: "some health services get fixated on 'the disability' and they lose sight of the big picture". As the below case study demonstrates, this 'blinkered vision' can significantly compromise the quality of healthcare offered to the person with the disability.

[10] Australian Institute of Health and Welfare 2000 *Disability and Ageing: Australian Population Patterns and Implications*, p.50 available at http://www.aihw.gov.au/publications/dis/da/da.pdf.

[11] Article 25, *Convention on the Rights of Persons with Disabilities* 13 December 2006 (entered into force 3 May 2008).

CASE STUDY – SEEING THE DISABILITY, NOT THE PERSON

Glenys is a woman in her late 60s who lives in a community residential unit. One day, Glenys had a bad fall at the unit. She was worried that she might have broken a bone, so she attended the emergency department for a physical examination. The hospital staff were aware that Glenys had mental health issues and they immediately directed her to a mental health facility. They did not examine Glenys or address her concerns about the fall.

5.3 In order to facilitate optimal healthcare for people ageing with a disability, the interface between the healthcare and disability sectors needs to be better developed. OPA believes that these sectors need to implement policies that address the systemic difficulties experienced by people with disabilities in accessing optimal healthcare. Capacity must also be created for the development of specialist health knowledge and services that respond to the specific needs of people ageing with a disability.[12]

5.4 Respite is another important aspect of health promotion for people ageing with a disability and, of course, for their carers. On this point, OPA's Community Visitors consistently report chronic levels of respite shortages in Victoria. These shortages are compounded by the fact that respite services are being inappropriately used as long-term accommodation for people with disabilities who have nowhere else to go.[13] OPA is concerned for the welfare of people in this situation, and emphasises that respite cannot be a substitute for a home.

5.5 Inevitably, this misuse of resources means that there are even fewer beds available for genuine respite purposes. Anecdotal evidence suggests that carers routinely get less respite than what they ask for, or, as is increasingly the case, they miss out altogether. OPA is concerned that this phenomenon places an additional and unnecessary strain on people with disabilities and their carers. OPA therefore urges the government to address the shortfalls in both permanent and respite accommodation places as a matter of priority.

CASE STUDY – NOWHERE TO GO

Jim is a man in his 60s who has an intellectual disability, Autism and difficulty mobilising. Jim's parents were his life-long carers. As Jim's parents got older, they found it increasingly difficult to continue looking after him. When Jim's father died, his mother found she simply couldn't cope on her own. She dropped Jim off at a respite centre and didn't come back. Jim has been living in respite for nearly one year. His new carers have tried to find him alternative accommodation but, as yet, nothing suitable has come up.

[12] Fyffe, C., Bigby, C. and McCubbery, J. *Exploration of the Population of People with Disabilities Who Are Ageing, Their Changing Needs and the Capacity of the Disability and Aged Care Sectors to Support Them to Age Positively*, p.11.

[13] OPA, *Community Visitors Annual Report 2009*, p.27.

RECOMMENDATIONS

4. That the healthcare and disability sectors develop and implement policies that address the difficulties experienced by people with disabilities in accessing optimal healthcare.

5. That the government address the shortfall in the numbers of permanent and respite accommodation places.

6. Planning Ahead

6.1 The Inquiry has asked respondents to "identify any inadequacies" in the "planning options" for people ageing with a disability and their carers.[14] OPA considers that this question is one that requires immediate attention at a national level. Currently, there is not enough knowledge about Australians ageing with a disability and those who support them. This lack of knowledge seriously compromises the government's ability to effectively plan for this group of people. OPA therefore urges the government to undertake a comprehensive national review of the characteristics and needs of this population.

6.2 OPA draws the Inquiry's attention to research that is currently being undertaken into the needs of older people with disabilities in Victoria. OPA is a partner investigator on an Australian Research Council funded research project examining the 'capacity of community residential units to facilitate ageing in place for people with intellectual disability'. The project is being run by Professors Webber (Australian Catholic University), Bigby (La Trobe University) and Bowers (University of Wisconsin-Madison), and follows on from previous work done by this group.[15] This research will provide important information for future planning, and should be used to inform a broader, national review of disability and ageing.

6.3 OPA recognises that one of the difficulties in undertaking such a review stems from the isolation experienced by many people ageing with a disability and their carers. Anecdotal evidence suggests that there are many people with disabilities living with older parents/carers who have never received social services (indeed, some of these people may not have been assessed as having a disability). Typically, the first time these people come to the attention of OPA is when their situation reaches crisis point. In OPA's experience, this often happens when parents die or simply cannot continue caring for the person with a disability.

[14] Senate Community Affairs Committee 2009 *Inquiry into Planning Options and Services for People Ageing with a Disability*, Terms of Reference.

[15] Bigby, C. Webber, R. Bowers B. & McKenzie-Green, B. 2008 'A Survey of People with Intellectual Disabilities Living in Residential Aged Care Facilities in Victoria' *Journal of Intellectual Disability Research*, pp.1-11.

6.4 The above scenario raises several issues in terms of planning. First, OPA emphasises the importance of linking these families in with services and support at an early stage. This is a difficult, but not impossible, task. It has come to OPA's attention that, while health and community organisations may be aware that these families are experiencing difficulties, they sometimes fail to make referrals to appropriate services. As one OPA staff member commented: "they see something's wrong, but they don't follow up on it". OPA believes that the willingness of these types of organisations to 'get involved' at an early stage is an essential part of counteracting the isolation experienced by many people with disabilities and their carers.

6.5 A further issue relates to the need to plan for effective transitions between the different life circumstances experienced by people with disabilities. For example, people with disabilities who have always lived in the family home may feel overwhelmed by the death of their parents and the resulting move to shared supported accommodation. These people should be given the option of utilising grief counselling and support to help them to adjust to their new situation. There also needs to be a clearer handover process for people moving from disability accommodation to aged care facilities. For example, a case manager or disability support worker could be utilised to provide advice and assistance to the person with the disability and to aged care staff. This type of service would facilitate the sharing of expertise between aged care and disability services, providing a much-needed link between the two sectors.

6.6 The importance of planning for such issues is palpable in light of the fact that people ageing with disabilities and their carers are an emerging population. While it is possible to highlight some of the challenges this population faces, the extent of these challenges are not yet known. One OPA staff member observed that: "we know there's a problem out there, but we don't know how big it is". This underscores the need for a whole-of-government, evidence-based response to the challenges presented by this population. Moreover, any such response must be guided by the need to protect and promote the rights, dignity and welfare of people ageing with a disability and their carers.

RECOMMENDATIONS

6. That a national review be undertaken of the population characteristics and support needs of Australians ageing with disabilities and their carers.

7. That the aged care and disability sectors develop and implement protocols for enabling people ageing with disabilities to make effective accommodation and care transitions. These protocols should include measures for improving the health and wellbeing of people with disabilities, including the provision of services such as grief counselling and case management where necessary.