



Intellectual Disability and Ageing:  
Canvassing the issues

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## 1. Preamble

This project is a consequence of discussions held between the Australian Catholic University and Catholic Social Services Victoria, and its member agencies, about where they saw the gaps in service delivery and what were the emerging issues for them as service providers. A critical issue that emerged from those initial conversations was the belief that older adults with an intellectual disability were being inappropriately placed in residential aged care facilities and that there needed to be put in place better protocols and relationships between the differently funded and organised disability and aged care service systems. There were also concerns expressed of ageing parents who are still caring for their adult offspring with an intellectual disability.

It was originally intended that two discrete – but inter-related - projects would be undertaken. One was to focus upon the perspectives of older parents and how they experienced caring for an intellectually disabled adult child. The second project was to focus upon the service system itself and how the disability and aged care sectors engage with one another. However, following further meetings and discussions it was decided that there had been significant work already undertaken on ageing carers and that both the Federal and State Governments had responded with policy and funding initiatives.<sup>1</sup>

The purpose of this scoping project, therefore, is to initially explore some of the issues facing individuals themselves, their family members and service providers, both from disability and residential aged care services, as people with an intellectual disability age and may then go on to require assistance from the aged care sector. This project will also provide background information on State and Federal policies in this area.

Because this was a scoping project only, a total of sixteen interviews were undertaken, of which fourteen were taped and transcribed in full. Of those interviewed, seven were disability service providers, four interviews were held with consumers and their families (a total of eight people), two were held with policy representatives, one interview was held with a representative from a carers' peak body, one was held with a representative from a disability peak body and one was held with an aged care service provider. The interviews were not intended to be representative of a sample of the relevant population. Given the tight timeframes for the project this was not feasible and nor was it necessarily appropriate for a project that was designed to briefly sketch out the issues.

For the purposes of this report, an older person will be defined as someone aged 55 years and above. This is consistent with definitions adopted in other countries, such as the United States, where Janicki and Ansello have argued that, although there has been considerable debate in that country about precisely when middle age for people

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<sup>1</sup> Although such initiatives are not adequate to meet the level of demand.

with an intellectual disability started, most of the states have adopted 55 or 60 years as the starting point of old age.<sup>2</sup>

In Australia, Gatter has argued that although chronological age will vary, “almost all would be expected to be aged 45 years or more, and most would be expected to be 50 years of age or more”.<sup>3</sup> Nonetheless, as Bigby has noted, there is a trend emerging “to counter the stereotype of premature ageing and adopt in relation to people with an intellectual disability the more conventional age of 60 years used for the rest of the population.”<sup>4</sup> But, as Bigby further notes, when it comes to actual service delivery, service providers tend to be somewhat more flexible in their approach to this question.<sup>5</sup>

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<sup>2</sup> M. Janicki & E. Ansello, “Supports for Community Living. Evolution of an Aging with Lifelong Disabilities Movement. In M.P. Janicki & E.F. Ansello, eds., *Community Supports for Aging Adults with Lifelong Disabilities*. Paul Brookes Publishing, Baltimore 2000. pp. 531-532.

<sup>3</sup> B. Gatter, *The Service Needs of People With A Disability Who Are Ageing*. Disability Services Commission, Western Australia September 1996. p. 12.

<sup>4</sup> C. Bigby, *Ageing with a Lifelong Disability. A Guide to Practice, Program and Policy Issues for Human Service Professionals*. Jessica Kingsley Publishers, London 2004. p. 41.

<sup>5</sup> *Ibid.* pp. 41-42.

## 2. Introduction

Over the past two to three decades, the industrialised countries have been slowly coming to terms with the implications of population ageing. Whilst this is not necessarily happening within each country to the same extent or at the same pace, for example some of the European countries have already experienced the ageing of their populations to a degree that is still anticipated in Australia, it is nonetheless a political reality for all developed countries.<sup>6</sup> Furthermore, population ageing is a reality that demands some very concrete policy solutions across a wide range of areas including aged care services, employment, health services and pharmaceuticals to name but a few.

Table 1 provides estimates of what population ageing might mean in raw numbers for different age cohorts over the next forty years. The table also illustrates where the largest percentage gains will occur.

**Table 1: Ageing of the Australian Population 2003-04 to 2044-45<sup>7</sup>**

Age	Increase in numbers	Percentage change
	People	%
0 to 14	549 053	13.8
15 to 64	3 325 141	24.6
65 plus	4 318 162	165.8
65 to 74	1 664 505	121.4
75 to 89	2 133 957	189.1
90 to 99	474 166	471.8
100 plus	45 534	1051.8
All ages	8 192 356	40.7

As the table suggests, the largest percentage increases will occur amongst cohorts known as the “old, old” – those aged over 85 years. Whilst the percentage increases presented in Table 1 for those aged between 75 and 100 plus years look to be quite extreme when compared to the small increase predicted in the 0 to 14 years group, it does need to be borne in mind that they are large increases of a very small base.

The figures presented in Table 2 below illustrate this point well. These figures show increases by both age and gender which suggest that by 2021 the number of people aged over 65 years will comprise around 19% of the population, while those in the category of “old, old” – that is, those aged over 85 years – will be about 1.9%. By 2044-45, the Productivity Commission has recently argued that more than one in four Australians will be aged over 65 years – up from the current level of 2.5 million to around 7 million people.<sup>8</sup>

<sup>6</sup> The developing countries are facing their own, very different, form of population ageing.

<sup>7</sup> Productivity Commission, *Economic Implications of an Ageing Australia*. Research Report. Productivity Commission, Canberra March 2005. p. 9.

<sup>8</sup> Productivity Commission, *Economic Implications of an Ageing Australia*. Draft Research Report. Canberra. 2004. p. xx.

**Table 2: Population estimates by age and sex between 1991 and 2021<sup>9</sup>**

Age/sex	1991	2001	2011	2021
<b>Females</b>				
65-75	633,500	676,900	847,000	1,243,200
75-85	370,900	486,600	544,300	705,800
85+	111,000	179,400	256,000	300,800
<i>Total females 65+</i>	<i>1,114,500</i>	<i>1,343,000</i>	<i>1,647,300</i>	<i>2,249,800</i>
<i>Total females</i>	<i>8,668,600</i>	<i>9,754,100</i>	<i>10,688,800</i>	<i>11,512,100</i>
<b>Males</b>				
65-75	548,600	628,400	820,200	1,184,500
75-85	243,400	350,800	435,400	608,400
85+	44,200	80,900	133,700	177,800
<i>Total males 65+</i>	<i>836,300</i>	<i>1,060,100</i>	<i>1,388,700</i>	<i>1,970,700</i>
<i>Total males</i>	<i>8,615,400</i>	<i>9,667,200</i>	<i>10,600,000</i>	<i>11,414,300</i>
<b>Persons</b>				
65-75	1,182,100	1,305,300	1,667,200	2,427,700
75-85	614,300	837,500	979,600	1,314,100
85+	154,200	260,300	389,200	478,600
<b>Total 65+</b>	<b>1,950,700</b>	<b>2,403,100</b>	<b>3,036,000</b>	<b>4,220,400</b>
<b>Total</b>	<b>17,284,000</b>	<b>19,421,300</b>	<b>21,288,800</b>	<b>22,926,400</b>

Despite these estimates, the longer term effects of an ageing population are largely unknown, primarily because such effects are mediated by productivity savings as well as medical and other innovations, which cannot be accurately predicted. However, this has not prevented “doom and gloom” scenarios being put forward in Coalition Government sponsored reports such as the National Commission of Audit report in 1996 and the *Intergenerational Report* brought down by the Treasurer Peter Costello in the 2002-2003 Federal Budget. Both of these reports have, to a greater or lesser extent, traded on the image of an unaffordable mass of older people all demanding expensive services at the cost of fewer and fewer people in the workforce to support them.

In an address to the Productivity Commission in 1999, Paul Johnson argued that negative connotations concerning population ageing arise because:

“it is widely believed that ageing will alter established economic and social relationships by affecting the rate of growth of the economy and the distribution of resources within the economy. Ageing is not alone in promising these effects – the globalisation of markets, the communications revolution, and bio-technology are all frequently identified as potential but unpredictable formative elements of social and economic life in the twenty-first century. But whereas these other prospects are more usually seen in positive rather than negative terms, population ageing is almost always seen as a problem because it is commonly believed it will reduce economic growth, and effect a redistribution that will reduce utility for at least some groups in society.”<sup>10</sup>

<sup>9</sup> AIHW, *Older Australia at a glance*. Third Edition. AIHW, Canberra 2002. p.4

<sup>10</sup> P. Johnson, “Ageing in the twenty-first century: implications for public policy”, Productivity Commission, *Policy Implications of the Ageing of Australia’s Population*. Productivity Commission, Melbourne 1999. pp. 11-12.

As Johnson suggested, the doom and gloom scenarios have revolved around who will pay for the large numbers of older people requiring services such as health care, pharmaceuticals and residential aged care services. Indeed, health care and pharmaceutical benefits were singled out in the *Intergenerational Report* as areas where significant growth in spending would occur unless major policy decisions were taken about how to fund such services.<sup>11</sup>

However, the Commonwealth Government's responses to population ageing have not entirely been based upon a negative scenario. For example, under the Coalition Government's *National Strategy for an Ageing Australia* a number of papers have been prepared which have sought to present a more positive picture regarding access, equity and affordability of services for older persons.<sup>12</sup> Although there is no equivalent in Australia to the "grey lobby" of the USA, there is nonetheless a strong desire by political parties of all persuasions not to alienate older persons through the introduction of policies which may be interpreted as unduly harsh or unjust.

The fact that politicians need to take note of, and listen to, the views of older people who comprise a growing and vocal segment of the population, therefore, often combines uneasily with the more economic statements concerning the distribution of resources and productivity levels and it has led Janicki and Ansello in the United States to ask what impact this might then have on the needs of people who are ageing with a lifelong disability.

"...the decreases in mortality and morbidity and the extension of life expectancy carry none of the urgency of crises such as economic depression or virulent epidemics. If this is so, what are the implications for ageing with lifelong disabilities when this phenomenon is occurring amidst a demographic evolution that is coloured, if at all, with positive and noncrisis tones? For instance, will the general population's improving health status add to or detract from a focus on older adults with lifelong disabilities? Will decreasing rates of morbidity and disabilities highlight the needs of these older adults by contrast, or will their needs become further marginalized as exceptions to overall population well-being? In short, is the ageing of the general population good for older adults with lifelong disabilities?"<sup>13</sup>

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<sup>11</sup> Commonwealth of Australia, *Intergenerational Report 2002-2003*. 2002-2003 Budget Paper No. 5. Commonwealth of Australia, Canberra May 2002. pp. 34-40.

<sup>12</sup> These papers cover such topics as healthy ageing, employment for older workers, services and lifestyle issues and include the following: B. Bishop, Minister for Aged Care. *The National Strategy for an Ageing Australia. Healthy Ageing Discussion Paper*. Commonwealth of Australia, Canberra 1999. B. Bishop, Minister for Aged Care. *The National Strategy for an Ageing Australia. Employment for Mature Age Workers Issues Paper*. Commonwealth of Australia, Canberra 1999. B. Bishop, Minister for Aged Care. *The National Strategy for an Ageing Australia. Independence and Self Provision Discussion Paper*. Commonwealth of Australia., Canberra 1999. B. Bishop, Minister for Aged Care. *The National Strategy for an Ageing Australia. World Class Care Discussion Paper*. Commonwealth of Australia, Canberra 2000. B. Bishop, Minister for Aged Care. *The National Strategy for an Ageing Australia. Attitude, Lifestyle & Community Support Discussion Paper*. Commonwealth of Australia, Canberra 2000.

<sup>13</sup> M. Janicki & E. Ansello, "Supports for Community Living. Evolution of an Aging with Lifelong Disabilities Movement. In M.P. Janicki & E.F. Ansello, eds., *Community Supports for Aging Adults with Lifelong Disabilities*. Paul Brookes Publishing, Baltimore 2000. p. 538.

Whilst this statement may appear to rely upon an exaggerated distinction between general population ageing and that occurring for people with an intellectual disability, it does serve as a timely reminder that approaches to general population ageing (as noted above) are frequently driven by normative assumptions. Such normative assumptions, of course, also tend to disguise ideological positions.

As we shall see, the scale of general population ageing has meant that it is only very recently that governments, public servants and service providers have acknowledged that there are sub-sets within that population who are also ageing and with whom the service system has had little experience to date. One of these sub-sets is older people with an intellectual disability.

### 3. The parameters of intellectual disability and ageing

#### 3.1 Ageing and disability

With regard to the combination of ageing and disability generally, there are two schools of thought about what is happening to the population. The first school of thought suggests that increased longevity has resulted in a compression of morbidity (the level and type of sickness within a population) at the end of life which could result in an actual decline in the prevalence of disability. The second school of thought argues that more people are surviving into old age who are frailer and that, therefore, there will be an increase in the prevalence of disability.<sup>14</sup> These schools of thought, as the Australian Institute of Health and Welfare makes clear, are “separated by differences in approach to measurement and underlying assumptions used”.<sup>15</sup>

These two differing interpretations of what may be happening at a general level makes understanding the data relating to ageing and disability highly complex. There are several reasons why this is so.

Although we have excellent estimates of population ageing generally and we have also had a series of reports by the Australian Bureau of Statistics (ABS) and the Australian Institute of Health and Welfare (AIHW) on disability and ageing, there is still considerable uncertainty about the numbers of people ageing with an intellectual disability. This uncertainty is partly driven by the fact that as people age their rates of disability also increase. It is, therefore, extremely important to distinguish between people who have a life-long disability who are themselves ageing from those whose disability may have been acquired as a function of the ageing process. Although they are both groups of older people who are ageing with a disability their life experiences are quite different from each other. The uncertainty is also partly driven by the fact that cognitive impairment has, in the past, included such age-related conditions as dementia.

Preliminary results from the ABS 2003 Survey of *Disability, Ageing and Carers* illustrates how ageing can affect the prevalence of disability. Thus, according to that survey the overall disability rate increased from just over 4% for people aged 0 to 4 years, to almost 41% for persons aged 65 to 69 years and 81% for those aged over 85 years.<sup>16</sup>

Analysis undertaken by the Australian Institute of Health and Welfare has found that for all people with a disability there was an increase in the proportion of people aged 65 years and over and a decline in the proportion aged under 65 years for the period 1981 and 1998.<sup>17</sup>

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<sup>14</sup> AIHW, *Disability and ageing: Australian population patterns and implications*. Canberra: AIHW 2000. pp. 11-12.

<sup>15</sup> *Ibid.* p. 11.

<sup>16</sup> ABS, *Disability Australia*. 2003 Preliminary. Cat. No. 4446.0. p.3. See also, ABS, *Disability, Ageing and Carers: Summary of Findings Australia*. Cat. No. 4430.0.

<sup>17</sup> AIHW 2000 op.cit. p. 83.

“Of total people with a disability, the proportion of those aged 65 years and over increased from 30.6% in 1981 to 35.4% in 1998. During the same period, among all people with specific restrictions the proportion of people aged 65 years and over increased from 34.4% to 37.0%.”<sup>18</sup>

### 3.2 Ageing with an intellectual disability

In terms of people ageing with an early onset disability, through an analysis of the surveys undertaken by the Australian Bureau of Statistics, the AIHW found the following:

- 11% of people with a severe or profound core activity restriction aged between 45 and 64 years had first experienced that disability before the age of 18;
- for people aged between 18 and 44 years, the corresponding figure was 48.6%;
- among people aged 65 years and over, only 4.1% of people with a severe or profound core activity restriction and 4.8% of people with a disability first experienced disability before the age of 18 years.<sup>19</sup>

Thus, although the figures reveal that people living with a lifelong disability are primarily younger, there is a small but steadily increasing proportion of people surviving now into older age. These are the people whom some researchers in the area of intellectual disability have referred to as healthier than younger cohorts because it is by virtue of their greater health status that they have survived longer. As the World Health Organisation has stated:

“It is important to underline the fact that many ageing persons with intellectual disabilities may be just as healthy as other older persons without life-long disabilities. This can be attributed to a quality lifestyle. It may also be due to ‘differential mortality’ – the tendency for healthier people to live longer. Thus, older cohorts may actually be healthier in many domains than younger groups of persons with intellectual disabilities, and show greater functional abilities until the oldest ages.”<sup>20</sup>

These views are supported by the work of Walker and Walker in the United Kingdom where they argue that:

“...older people with learning difficulties are likely to have lower levels of learning difficulty than younger cohorts. This difference has mainly come about because babies with severe learning difficulties who were born over 50 years ago would have had much less chance of surviving into adulthood than their contemporary counterparts.”<sup>21</sup>

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<sup>18</sup> Ibid.

<sup>19</sup> Ibid. p. 95.

<sup>20</sup> World Health Organisation, *Ageing and Intellectual Disabilities – Improving Longevity & Promoting Healthy Ageing: Summative Report*. Who, Geneva 2000. p.7.

<sup>21</sup> A. Walker & C. Walker, “Normalisation and ‘Normal’ Ageing: the social construction of dependency among older people with learning difficulties”. *Disability & Society* Vol. 13, No. 1 1998. p. 126.

In relation specifically to people aged over 65 years, the AIHW found in 1998 that only some 3700 people with a disability reported an intellectual disability as their main condition out of a total number of 212,700 (or around 1.1% of the Australian population) who reported an intellectual disability as their main disabling condition.<sup>22</sup> However, this figure needs to be treated with considerable caution as people living in cared accommodation were not asked about the age of onset of their disability but people living in other forms of accommodation were asked that question.<sup>23</sup>

These figures are broadly consistent with those presented by Bigby. In her analysis, which was based on both the ABS population projects and Wen’s estimated prevalence of people with an intellectual disability aged 55 years and over at 0.13%, she stated that the estimated number of people aged 55 years and over with an intellectual disability across Australia in the year 2000 was 5323.<sup>24</sup> The following table presents Bigby’s estimates for Australia and Victoria from 2000 to 2020.<sup>25</sup>

**Table 3: Projected number of people with an intellectual disability in Australia and Victoria Between 2000 and 2020.**

Year	2000	2005		2010		2015		2020		
	No.	No.	% change	No.	% change	No.	% change	No.	% change	% change 2000-2020
Victoria	1348	1533	14%	1719	12%	1910	11%	2090	9%	55%
Australia	5323	6161	16%	7046	14%	7984	13%	8921	12%	68%

As the above table illustrates, although the numbers of people ageing with an intellectual disability are small – less than 2100 people in Victoria by 2020 – they are increasing at a rapid rate. This tends to support the conclusions of a number of researchers mentioned above that today’s older people with an intellectual disability are survivors. The figures also suggest that such rapid increases – albeit from a tiny base – demand urgent policy and service responses.

Indeed, Barbara Gatter has written that these are the group for whom the 1950s and the 1960s could be regarded as a watershed:

“as this was the era when some parents began to make choices, against the conventional wisdom, to care for their children at home rather than to place them in institutional care. It is the impact of this latter ‘historical period’ which is now being felt in terms of service needs of people with a disability as they age.”<sup>26</sup>

<sup>22</sup> AIHW, “Estimates of prevalence of intellectual disability in Australia”. *Journal of Intellectual & Developmental Disability* Vol. 29, No. 3. 2004. p. 285.

<sup>23</sup> AIHW, *Disability and ageing: Australian population patterns and implications*. Canberra: AIHW 2000. pp. 95-100.

<sup>24</sup> C. Bigby, *Ageing with a Lifelong Disability*. Jessica Kingsley Publishers, London 2004. p. 43.

<sup>25</sup> *Ibid.* p. 45.

<sup>26</sup> B. Gatter, *The Service Needs of People With a Disability Who Are Ageing*. Disability Services Commission, WA September 1996. p. 11.

Thus, not only are we witnessing the survival of a particularly healthy group of older people with an intellectual disability into old age but we are also seeing the emergence of a group, the majority of whom have not necessarily spent their lives in an institution. These needs are the subject of a later section of this report.

#### 4. Theoretical approaches to ageing and intellectual disability

The consumer and self-advocacy movement for people with disabilities began to emerge in countries such as the United States and Britain in the 1960s. As some researchers have written prior to that emergence (and indeed subsequently in some discourses): “To have an impairment was regarded as a ‘personal tragedy’ – a conclusion which united service providers, policy-makers and the wider public. It seemed to dictate a life as a passive ‘victim’ characterised by social exclusion and disadvantage, and by dependency on assistance from family and friends and a ‘safety net’ of state welfare benefits and services.”<sup>27</sup>

It is this notion of life as a ‘victim’ and as someone who is dependent that can render the experiences of older people with an intellectual disability as non-normative in the sense understood by Janicki and Ansello in their quotation above<sup>28</sup> and which then possesses the potential to lead to the further marginalisation of this group of older people in our society.

But, as Barnes and Mercer have pointed out, the first major challenge to the individualised or ‘personal tragedy’ approach to disability occurred with the model developed by the Union of the Physically Impaired Against Segregation (UPIAS) in 1976.

In their manifesto, UPIAS declared: “In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.”<sup>29</sup> This social model of disability is built upon a clear separation between the definitions of impairment and disability. Impairment refers to the physical or cognitive condition but disability refers to the restrictions imposed by contemporary social organisation. Thus, for example, for people with physical disabilities, the disability would be caused by lack of access to buildings and other environments which would enable them to participate fully in society.

Despite the fact that the UPIAS manifesto was issued almost thirty years ago, it is only recently that people with an intellectual disability have been included as among the oppressed groups of people with disabilities, by either researchers or disability groups themselves. As a recent article has suggested:

“Writers committed to the social model have applied it with great enthusiasm to physical and sensory impairment, but they have neglected people with learning difficulties...The separation of literature of the social model and the literature associated with learning difficulties has created distinct ways of doing research. While the former aims to engage with emancipatory disability research, the latter fits with an interpretative or

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<sup>27</sup> C. Barnes, G. Mercer & T. Shakespeare, *Exploring Disability. A Sociological Introduction*. Polity Press, Cambridge 1999. p. 10.

<sup>28</sup> See above p. 5.

<sup>29</sup> C. Barnes & G. Mercer. *Disability*. Polity Press, Cambridge 2003. p. 11.

enlightenment model, based on the twin objectives of empathising with people's experiences, and advocating service change to planners and providers... Walmsley argued that normalisation continues to influence the self-advocacy movement. In explaining the oppression of people with learning difficulties, she noted that the self-advocacy movement tends to emphasise issues associated with negative labelling (drawing on normalisation) rather than the consideration of disabling social and economic structures as set out by supporters of the social model."<sup>30</sup>

There are several reasons why people with an intellectual disability were not originally included in the work of activists and theorists. In the first instance, a significant number of people with intellectual disabilities have experienced life-long marginalisation in terms of access to education, employment and – although this is now changing – where and how they live. The same is not necessarily true for other forms of disability some of which may either have not precluded access to mainstream facilities and opportunities or which may have occurred at a later stage in life.

A second, and perhaps more fundamental, reason why people with intellectual disabilities were frequently excluded concerns the influence of the Canadian social scientist Wolf Wolfensberger. Wolfensberger has become renowned for his work on 'normalisation' and 'social role valorisation'. Wolfensberger's theory of normalisation "encompassed egalitarian initiatives to generate an environment for people with learning difficulties that offered as 'normal' a life as possible, although this did not necessarily mean their removal from segregated institutions".<sup>31</sup> His theory of social role valorisation, on the other hand, represented the "creation, support and defense of socially valued roles for people who risk devaluation".<sup>32</sup> According to Dowse: "This principle served to accord professionals a central role in interpreting disabled people's socially valued roles and activities thereby investing them with the legitimacy and power to advocate for people with learning difficulties."<sup>33</sup>

Effectively, whilst other groups of people with disabilities were challenging the social construction of their disabilities and also therefore, implicitly if not explicitly, the societies in which they lived, people with intellectual disabilities were being emancipated from institutions to live with 'normal' people in a 'normal' society. This did not, however, represent a challenge to the foundations of that society.

Indeed, according to Barnes and his colleagues:

"Critics have suggested that whatever 'normalisation' achieves for disabled people, it facilitates professionals' adaptation to new policies on

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<sup>30</sup> A. L. Chappell, D. Goodley & R. Lawthom, "Making connections: the relevance of the social model of disability for people with learning difficulties", *British Journal of Learning Disabilities*, Vol 29 2001. pp. 46-47.

<sup>31</sup> E. Emerson, "What is Normalisation?" in H. Brown & H. Smith, eds., *Normalisation: A Reader for the Nineties*. Tavistock, London 1992. Cited in L. Dowse, "Contesting Practices, Challenging Codes: self advocacy, disability politics and the social model". *Disability & Society*. Vol. 16, No. 1, 2001. p. 134.

<sup>32</sup> W. Wolfensberger, "Social Role Valorisation: a proposed new term for the principle of normalisation". *Mental Retardation*, Vol. 21, No. 6, 1983. p. 234. Cited in Dowse, op.cit. p. 134.

<sup>33</sup> Ibid.

de-institutionalisation and community-based service provision. ‘Normalisation’ does not challenge the legitimacy of the professional role in the lives of disabled people, but guarantees its continued authority. The whole focus of this approach is on changing disabled people to make them more like ‘normal’ people rather than challenging the idea of ‘normality’.”<sup>34</sup>

Furthermore, Barnes and his colleagues go on to suggest that, in contradistinction to the social model of disability, “Wolfensberger’s technological determinist approach contains little explanation of the historical relationship between industrial capitalism, the state, professions and disability”.<sup>35</sup> The influence of normalisation theory is particularly evident in Australian government policies – both state and national – which have tended to stress a human rights approach since the early 1980s. These policies will be examined in the next section of this report.

Despite these criticisms, it does need to be acknowledged that “for many people with an intellectual disability there has been a tremendous shift towards a more ‘normal’ way of life. The life story work of people with an intellectual disability...illustrates all too clearly the joy experienced by people with an intellectual disability at seeing the doors of long-stay hospitals finally close and new doors open for them.”<sup>36</sup> The purpose of presenting these theoretical approaches is not, therefore, intended to devalue the very real and important gains made by advocates of normalisation.

Nevertheless, the point remains that for older people with an intellectual disability the application of normalisation may simply mean substituting one form of negative stereotyping for another. As Walker and Walker have said:

“It is reasonable to ask what is ‘normal’ for any particular group in society? Is what is regarded as ‘normal’ or widely accepted as such, a desirable optimum or the result of historical development or just a matter of resource constraints? What is ‘normal’ is not necessarily ideal or even appropriate...the limitations of the normalisation concept are clearly demonstrated with regard to older people with learning difficulties because the experiences of their reference group – in this case older people – are themselves often limited and restricted by society’s attitudes. Thus, the goals set for older people with learning difficulties and the service responses offered to them will, in turn, be restricted by the socially constructed stereotype of old age as a period of dependency.”<sup>37</sup>

More recently, and following on from the theory’s apparent inability to include intellectual disability, researchers have started to address what they perceive as some drawbacks within the social model of disability itself particularly in relation to people with intellectual disabilities. The problem, as Goodley points out is that: “whereas

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<sup>34</sup> C. Barnes, G. Mercer & T. Shakespeare op.cit. p. 74.

<sup>35</sup> Ibid.

<sup>36</sup> A. Culham & M. Nind, “Deconstructing normalisation: clearing the way for inclusion”. *Journal of Intellectual and Developmental Disability*. Vol. 28, No. 1. p.70.

<sup>37</sup> A. Walker & C. Walker, “Normalisation and ‘Normal’ Ageing: the social construction of dependency among older people with learning difficulties”. *Disability & Society*. Vol. 13, No. 1 1998. pp. 129-130.

people with physical impairment are rightfully afforded a socio-historical position in the social model...people with 'learning difficulties' are consistently underwritten."<sup>38</sup> Instead, Goodley suggests that "we need to enter into a dialogue about the *possible and perhaps necessarily exaggerated social origins* of the 'learning difficulties impairment' *per se*".<sup>39</sup>

"An awareness and acceptance of their (diagnostic criteria) external origins invites us to destabilise taken-for-granted embodied notions of 'impairment' and pushes us towards an understanding of people with 'learning difficulties' that recognises their resilience in the face of arbitrary 'scientific' categorisations that have historically denied their humanity altogether. *Impairment's alliance with the 'natural' is questioned and its social origins investigated.*"<sup>40</sup>

The importance of this challenge is that it extends the social model to the so-called 'natural' area of the disability itself, thereby revealing that what is 'written on the body' is as much a social construct as the disability that is said to flow from the impairment. Thus, if the social model originally represented an attack upon the medical model of disability, later theorists have sought to expose the ideological bases upon which seemingly 'objective' medical judgements are made regarding the biological 'fact' of impairment.

More recently still, some theorists, such as Rapley, have adopted a post-structuralist approach to disability which is strongly influenced by the work of Foucault, particularly his emphasis upon surveillance and control which can transcend a particular material setting or environment. This represents perhaps a logical 'next step' for those theorists who were starting to question the natural bases of impairments. Thus, as McIntosh has argued:

"Emancipated from institutions, people with learning disabilities now undergo assessment of their strengths, capabilities and weaknesses. Every deficiency is logged and plans are drawn up to correct this. The process is monitored and evaluated, the person a subject of social demand and professional obligation. Minutiae of lives and thought are explored, interpreted, and broadened to a wider audience."<sup>41</sup>

But if this analysis is correct regarding surveillance and control, it lacks any obvious resolution. This has always been one of the fundamental problems with Foucault's imbrication of power and knowledge in his discourse.<sup>42</sup> Thus, one of the difficulties associated with the adoption of a 'pure' Foucauldian approach is that it has the tendency to see professional power as unidirectional rather than as also containing the possibility for undermining such apparently monolithic discourses of power and

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<sup>38</sup> D. Goodley, "'Learning Difficulties', the Social Model of Disability and Impairment: challenging epistemologies". *Disability & Society*, Vol. 16, No. 2, 2001. p. 211.

<sup>39</sup> *Ibid.* p. 213. Italics in the original.

<sup>40</sup> *Ibid.* Italics in the original.

<sup>41</sup> P. McIntosh, "An Archi-texture of Learning Disability Services: the use of Michel Foucault", *Disability & Society*, Vol. 17, No. 1, 2002. p. 73.

<sup>42</sup> See, for example, L. McNay, *Foucault. A Critical Introduction*. Polity Press, Cambridge 1994. pp. 63-64.

knowledge. A further problem lies with the return to an individualised approach or, perhaps to be more accurate, the lack of a collective approach to oppression and political action, that is evident in Foucault's work.

Few researchers have attempted to theorise ageing and disability together. A rare exception is the – albeit preliminary - work undertaken by Jae Kennedy and Meredith Minkler in the United States. With echoes in the statement made by Janicki and Ansello that greater stress upon decreasing rates of morbidity and disabilities for older people might result in greater marginalisation of older people with life-long disabilities such as intellectual disability, Kennedy and Minkler have said that there has been an ongoing, and not necessarily productive, effort on the part of ageing advocates to disentangle ageing from disability:

“This has led some researchers to contrast ‘successful ageing’ (i.e., avoiding functional limitation through exercise, diet, and appropriate medical care) with ‘usual ageing’. Although this distinction is a usual one – for example, in underscoring the importance of health promotion over the life course – a problematic consequence of this sort of dichotomy involves the potential for further stigmatisation of older persons with disabilities.”<sup>43</sup>

Kennedy and Minkler suggest that a two-fold process may be occurring for people who both have a disability and are ageing. Thus, whilst for the older population generally greater emphasis is being stressed upon the attainment or continuation of such conditions as autonomy and growth, this is not so for older people with a disability, where expectations are dramatically lower. At the same time: “Where ‘access’ and ‘full participation’ have become key concepts for the younger disabled population, the sights of families and professionals, and of older disabled persons themselves, tend to be far more circumscribed. In this way, ageing professionals, elders, and society in general appear to have traded earlier, limited views of ageing for an even more limited view of what it means to be old and disabled.”<sup>44</sup>

These views are coterminous with those expressed by Walker and Walker who have long argued that whilst normalisation has been criticised for neglecting gender, race and class, the same could be said for age. Indeed, they argue that this is even pertinent in a context where normalisation has given way to social role valorisation.

“Although normalisation theory hinges on the position of the individual, in the process of operationalising it for the purposes of service delivery, attention is inevitably concentrated on group needs, interests and expectations and, if it is inappropriately applied, this can lead to stereotyping. In the case of older people, of course, the risk consists of age stereotyping. Normalisation is concerned with what is socially valued. However, where the reference or peer group within the wider community i.e. older people in general, is itself not socially valued and where the main models of care provided for the wider group neither aspire to nor achieve

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<sup>43</sup> J. Kennedy & M. Minkler, “Disability Theory and Public Policy: Implications for Critical Gerontology”. *International Journal of Health Services*. Vol. 28, No. 4, 1998. p. 758.

<sup>44</sup> *Ibid.* pp. 768-769.

the core values of normalisation, then, unless challenged, the goals set for older people with intellectual disabilities will be constrained.”<sup>45</sup>

Effectively, some commentators have suggested that older adults with an intellectual disability face a situation of double jeopardy where they are at risk of receiving second rate services from both the disability and aged care service systems because they are seen to be the primary responsibility of neither.<sup>46</sup>

It is in order to counter this ‘double jeopardy’ that Kennedy and Minkler argue for an alliance between the political economy approach of social gerontology and what they call the independent living movement in the area of disability. For them, this involves a movement “towards a moral economy of interdependence, which moves beyond narrow conceptualisations of needs, rights, and entitlements to focus instead on a broad vision of reciprocity. Instead of segmenting the needs of the elderly and disabled, we should acknowledge as a society the ‘webs of interdependence’ in which all members of the national community live.”<sup>47</sup> Whilst operating within a political economy perspective, which clearly shares many details with the social model of disability, Kennedy and Minkler effectively also argue from a humanistic or enlightenment perspective which denies rugged individualism and, instead, stresses our reliance upon others. This is not necessarily a theoretical approach to replace either normalisation or social role valorisation but, rather, it is perhaps better described as offering a way forward for both service users and service providers.

Although this discussion may appear somewhat esoteric, such theoretical approaches have had a significant influence on disability policy directions in Australia and this is the subject of the following section of this report.

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<sup>45</sup> A. Walker & C. Walker, “Age or disability? Age-based disparities in service provision for older people with intellectual disabilities in Great Britain”. *Journal of Intellectual & Developmental Disability*. Vol. 23, No. 1. 1998. p. 28.

<sup>46</sup> See, for example, R. Bland, N. Hutchinson, P. Oakes & C. Yates, “Double Jeopardy? Needs and services for older people who have learning disabilities”. *Journal of Learning Disabilities*. Vol, 7, No. 4. 2003. p. 327.

<sup>47</sup> Kennedy & Minkler. op.cit. pp. 772-773.

## 5. The policy environment

As we have seen, some researchers have spoken of individuals who are ageing with an intellectual disability as in danger of a double jeopardy. Whilst this may not mean the same across different countries, it suggests that the ageing and disability service systems in various countries are not only divided by their differing philosophical approaches but also by their very mode of organisation and funding. In Australia, where Federal/State relations come into play, this has proved to be a particularly pertinent issue.

In terms of philosophical approaches, the differences between the two systems are seen largely in terms of their approach to the capacity of individuals. Thus, it is argued that aged care services are based largely upon a perception of decline, leading inexorably to death. Demands are therefore fewer and expectations are lowered. By contrast, disability services are based upon a developmental approach.

How these differences have translated into practice has been judged by a number of qualitative studies. For example, in her study of service use by 62 older people with an intellectual disability, Bigby found that: “Concerns expressed about disability services differed from those expressed about aged-care services. Informants were critical of the quality and appropriateness of aged-care residential services and, in contrast, were critical of decisions, administrative processes and the availability of disability services.”<sup>48</sup>

Responsibility for the funding and delivery of aged care services is split between all three levels of government – national, state and local. Disability services, on the other hand, are effectively a state responsibility. They are, however, subject to the broad parameters laid out in the regularly negotiated Commonwealth State/Territory Disability Agreement which is signed by the Commonwealth and all the states and territories. Disability services are also subject to the bi-lateral agreements signed by the Commonwealth and individual states and territories.

In a review of disability policy over the twelve years that Labor was in power at a Federal level, Mary Lindsay said:

“Commonwealth policy in the last twelve years has both responded to, and in turn contributed to, moving the debate on from the negative stereotyping associated with our early history. Its emphasis is now (in 1996) on enhancing and protecting the rights of people with disabilities and providing opportunities for them to contribute to the wider society, both through the provision of disability specific services and through modifications to mainstream services to increase their accessibility...Most influential of these policies has been deinstitutionalisation through which...people with disabilities have moved from institution-based to community-based accommodation. Equally important is integration, which

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<sup>48</sup> C. Bigby, “Shifting responsibilities: The patterns of formal service use by older people with intellectual disabilities in Victoria”. *Journal of Intellectual & Developmental Disability*. Vol. 23, No. 3. 1998. p. 237.

has enabled people with disabilities to participate, where possible, in mainstream education, employment and recreation activities. The Commonwealth Government approach was intended to move the policy focus from services and service providers to individual consumers. Accordingly, consumer rights and the empowerment of people with disabilities figured prominently in policy debates during this period.”<sup>49</sup>

Thus, as Lindsay suggests, the last twenty years have seen a steady movement away from segregation and towards inclusion. Whether or not this has been a successful policy, it represents the triumph of normalisation and its corollary, social role valorisation, in policy making circles.

The first Commonwealth-State Disability Agreement came into operation in 1991. The purpose of the CSDA was primarily to rationalise the roles and responsibilities of the Commonwealth and the States as well as to introduce some form of consistency across the country in terms of service provision. This first agreement:

- gave the Commonwealth responsibility for employment, training and placement services for people with disabilities, and for print disability services;
- gave the States responsibility for accommodation support, information services, independent living training, recreation services and respite care; and
- gave joint Commonwealth-State responsibility for advocacy, research and development and involved both in planning, priority setting and program evaluation.<sup>50</sup>

In addition to these roles under the CSTDA, the Commonwealth Government’s main area of expenditure is in relation to income support payments.<sup>51</sup>

The current CSTDA, which expires in 2007, is based “on the premise that communities are enriched by the inclusion of people with disabilities and that positive assumptions about the gifts and capacities of people with disabilities, including those with high support needs, are fundamental to their experience of a good life and to the development and delivery of policy, programs and services.”<sup>52</sup>

The influence of normalisation theory, as stated above, is particularly pertinent in terms of this emphasis upon inclusion and human rights. The framework upon which the CSTDA rests embodies these underpinnings. But it also embodies the beginning of another major policy shift – from a focus upon services and programs to a focus upon the individual. This is, in effect, a fundamental shift (at least at the linguistic level) to an individual needs-driven service system. This framework rests upon the following five policy priorities and aims:

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<sup>49</sup> M. Lindsay, *Commonwealth Disability Policy 1983-1995*. Background Paper 2 1995-1996. Parliamentary Library, Canberra. [www.aph.gov.au/pubs/bp/1995-96/96bp06.htm](http://www.aph.gov.au/pubs/bp/1995-96/96bp06.htm)

<sup>50</sup> Ibid.

<sup>51</sup> In 2002-2003 income support payments to people with disabilities amounted to some \$7.3 billion.

<sup>52</sup> Department of Family & Community Services, *Agreement between the Commonwealth of Australia and the States and Territories of Australia in relation to Disability Services*. Third Commonwealth State/Territory Disability Agreement. FaCS, Canberra 2003. p. 2.

- a) strengthen access to generic services for people with disabilities by:
  - fostering a whole-of-government approach to maximise the opportunity for people with disabilities to participate socially and economically in the community; and
  - explicitly recognising access to, and the role of, generic services as a complement to the focus on the funding and delivery of specialist disability services and supports.
- b). strengthen across government linkages by:
  - positively influencing the service system within and external to the Agreement to ensure that full access to appropriate services is supported and strengthened; and
  - improving collaboration, co-ordination across programs and governments to ensure that people with disabilities have fair opportunities to access and transition between services at all stages of their lives.
- c). strengthen individuals, families and carers by:
  - developing supports and services based on individual needs and outcomes, which enhance the well-being, contribution, capacity and inclusion of individuals, families and carers; and
  - increasing their opportunities to influence the development and implementation of supports and service at all levels.
- d). improve long-term strategies to respond to and manage demand for specialist disability services through:
  - strategic approach to broad national and local/jurisdictional planning to underpin the determination and allocation of equitable funding to respond to unmet demand, growth in demand and cost increases; and
  - approaches which enhance prevention and early intervention outcomes, the effective co-ordination across service systems and clear and transparent decision making.
- e). improve accountability, performance reporting and quality by:
  - improving accountability and transparency for specialist disability services funded under this Agreement; and
  - incrementally developing, implementing and reporting progress on the aforementioned national policy priorities.<sup>53</sup>

As the policy priorities suggest, the CSTDA represents a very broad brush approach to disability policy. Although the language is that of normalisation, inclusion and human rights, it is difficult to gauge what these mean in practice, particularly for a very small group such as people ageing with an intellectual disability.

It is at the level of the bi-lateral agreement between Victoria and the Commonwealth, and how this translates into funding and programs, that a sense of the relationship between the theoretical underpinnings and policy and program development can be discerned.

Thus the five policy priority areas delineated above become translated into activity areas, for example:

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<sup>53</sup> Ibid. p. 12.

## Policy Priority 2: Strengthen across government linkages

### Activity areas:

- Improving consumer access within and across the support services that best meet their individual needs.
- Aged Care/Disability services interface.<sup>54</sup>

In terms of the Aged Care/ Disability Services interface, the bi-lateral agreement contains the following statement.

For older people with disabilities both parties will work together to develop:

- Improved assessment processes informed by an understanding of the needs of people with disabilities as they age.
- More flexible funding approaches, including shared funding where appropriate.
- To evaluate current models of support for people with a disability who are ageing and explore opportunities to pilot models that consider the needs of people ‘ageing in place’.
- Appropriate training and skills development for disability and aged care support staff to ensure that both sectors have an improved understanding of the support needs of people with disabilities as they age.<sup>55</sup>

Thus the bi-lateral agreement signed between Victoria and the Commonwealth represents the first formal acknowledgement that the two service systems of disability and aged care need to work together to achieve better outcomes for people who are ageing with a lifelong disability.

Yet, despite this acknowledgement, it is still difficult to comprehend precisely how this closer relationship will be achieved. If we look at the *State Disability Plan*, for example, which is the Victorian Government’s vision for disability services over the decade 2002-2012, there is little that is specifically focussed upon older people. This is not necessarily surprising, given that this is a plan for all people with a disability. Nevertheless, there is frequent mention of the needs of younger people.

The policy area where the State Disability Plan will perhaps have most impact relates to Individualised Planning and Support (this is also referred to as person-centred planning in some research). Here the Government states that this framework:

“will enable disability supports to be tailored to people’s individual needs. Individualised planning and support will enable people with a disability to live in the community and receive the support they need within the ordinary structures of education, health, employment and community services. It will focus on supporting people with a disability to develop and maintain their informal and formal networks. This approach recognises the importance of earlier planning and support to achieve the

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<sup>54</sup> Commonwealth of Australia and The State of Victoria. *A Bilateral Commonwealth State Territory Disability Agreement*. FaCS, Canberra 2003. p. 4.

<sup>55</sup> Ibid. p. 8,

best possible outcomes at all ages and stages of a person's life – as children, young people, adults and as people with a disability age.”<sup>56</sup>

Person-centred planning possesses the potential to break down barriers between service systems. As Mansell and Beadle-Brown have said:

“Firstly, it aims to consider aspirations and capacities expressed by the service user or those speaking on their behalf, rather than needs and deficiencies...Second, person-centred planning attempts to include and mobilise the individual's family and wider social network, as well as to use resources from the system of statutory services...The third distinctive characteristic of person-centred planning is that it emphasises providing the support required to achieve goals, rather than limiting goals to what services typically can manage.”<sup>57</sup>

But, whilst lauding this new direction, the authors also suggest that person-centred planning represents an extremely ambitious target for public policy. Indeed, the success or otherwise of these policy directions depends upon a number of crucial factors including available resources and the capacity of service systems to respond to new directions. Indeed, Bigby and Ozanne have argued that: “While intellectual disability policy is particularly strong on the articulation of values and principles, across Australia and other Western countries, a major weakness lies in policy implementation. The field is characterised by major gaps between policy and practice and high levels of unmet need.”<sup>58</sup>

Thus, Bigby's study of 62 older people with an intellectual disability found in 1998 that whilst “neither the Federal or the Victorian State Government have any specific policies in respect of older people with intellectual disability...the findings of the present study suggest an implicit policy of redirecting them toward the aged-care service system and withdrawing disability services operating at the level of service provision in Victoria.”<sup>59</sup>

The final section of this report looks at how people's needs are articulated and perceived, based primarily upon the interviews conducted.

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<sup>56</sup> Department of Human Services, *Victorian State Disability Plan 2002-2012*. DHS, Melbourne 2002. p. 18.

<sup>57</sup> J. Mansell & J. Beadle-Brown, “Person-Centred Planning or Person-Centred Action? Policy and Practice in Intellectual Disability Services.” *Journal of Applied Research in Intellectual Disabilities* Vol. 17, 2004. pp. 1-2.

<sup>58</sup> C. Bigby & E. Ozanne, “Shifts in the model of service delivery in intellectual disability in Victoria”. *Journal of Intellectual & Developmental Disability*. Vol. 26, No. 2. 2001. p. 179.

<sup>59</sup> C. Bigby, “Shifting responsibilities” op.cit. p. 239.

## 6. The needs of people ageing with an intellectual disability

According to the Australian Institute of Health and Welfare, the special situation of people ageing with an early onset disability has been summed up in the following key characteristics:

- They are more likely to have low levels of functional ability, which is often the main reason they require care, particularly residential care.
- They are less likely to use community services and facilities or participate in community activities without assistance.
- They are more likely to have low levels of education, particularly those with an intellectual or learning disability.
- Many of them have never been married and hence have no spouse or children. It is these family members who provide most informal support to older people with a late onset disability. Those relying on informal support from aged parents are at risk of losing their support.
- They are more likely to live in residential care and less likely to live alone or live with their families.
- They are less likely to have good social networks outside the family or their place of residence.
- They may be particularly disadvantaged due to lack of good communication skills. Many have difficulty expressing their needs or may require assistance to identify their needs.
- They have low participation rates in both formal and informal day activities and leisure programs, partly due to factors such as lack of good communication skills and informal support networks, partly because few opportunities or choices are available.
- The effects of long-term placement in residential care (including group homes) may have reduced their capacity to engage in community activities.
- They are more likely to have participated in supported employment. For those who have been in supported employment, this may have not only provided occupation throughout their adult life, but also have been the main source of their lifelong social relationships.
- They are more likely to be dependent on pensions and not have any retirement income.
- They are much less likely to be home owners.<sup>60</sup>

As this list shows only too clearly, many of the needs of older people who are ageing with an intellectual disability stem largely from their life circumstances. Furthermore, those life circumstances have been largely determined by how society has regarded people with an intellectual disability. Fundamentally, therefore, many of the needs outlined above are driven by society rather than by any special attributes of individuals themselves. The social model of disability would appear to be extremely relevant in this context.

Indeed, Christine Bigby has written:

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<sup>60</sup> AIHW. *op.cit.* p. 46.

“The life experiences of being a person with a disability impacts on the informal and formal support available and needs as a person ages. For example, few people with intellectual disability will have experience of paid employment during their adult years, typically their social networks are limited lacking a spouse or children, few would have accumulated assets for their retirement, and most will have had some level of dependency on formal or informal supports for support with tasks of everyday living...These factors differentiate people with a lifelong disability from others who are ageing and mean that they may have some different needs but also that similar needs may have to be met in a different manner. For example, the use of formal services in place of informal services.”<sup>61</sup>

In terms of where the needs of people ageing with an intellectual disability may lie, the AIHW reported:

“In the age group 45-64 almost 40% of people with a severe or profound core activity restriction and an intellectual main condition were living in cared accommodation – a much higher proportion than for other main condition groups...Among those aged 65 or more with a severe or profound core activity restriction, over 90% of those with an intellectual main condition were living in cared accommodation. People who have spent a large part of their life in cared accommodation are likely to face different issues and have different needs from those who have spent most of their life living in the community.”<sup>62</sup>

In terms of actual needs, the following have been identified:

- They have a high need for formal support services, particularly accommodation support services, since they often do not have good informal support networks and may lack independent living skills.
- They have a high need for age-appropriate day activity and leisure programs. Separate specialist activity programs may be required in addition to, or instead of, community-based services designed for older people generally.
- Appropriate activity services may be required for people with an early onset disability who have previously worked in either supported employment or open employment.
- They have a high need for assistance in choosing, locating, negotiating access and travelling to community-based programs, and may also require short-term or ongoing assistance in order to participate in chosen activities.
- They have a high need for assistance in expanding their social networks beyond their families’ and parents’ peer group.

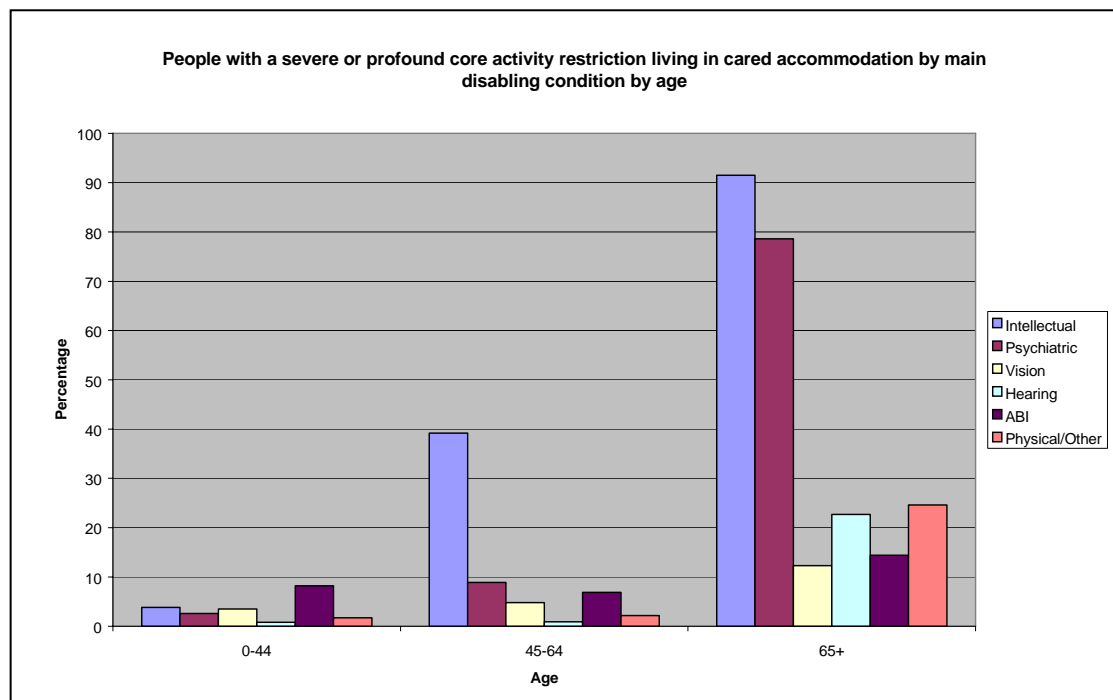
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<sup>61</sup> C. Bigby, “Ageing people with a lifelong disability: challenges for the aged care and disability sectors”. *Journal of Intellectual & Developmental Disability*. Vol. 27, No. 4. 2002. p. 232.

<sup>62</sup> AIHW, *Disability and ageing: Australian population patterns and implications*. Canberra: AIHW 2000. p.190.

- They may need special assistance in personal financial planning. The extra costs incurred by people with lifelong disability can mean that they face old age with few financial resources.
- The impact of disability changes throughout the life span and needs for support tend to increase with ageing. Therefore, reassessment of needs should be available to ageing people with a lifelong disability and they should be involved in initiating reassessments as required.<sup>63</sup>

Although place of residence is important for older people generally and, indeed, it drives the policy of ageing in place, it has an especial meaning for people ageing with an intellectual disability. The following chart provides some sense of the relative proportions of people living in cared accommodation by age and disability status.



Source: AIHW, *Disability and Ageing. Australian population patterns and implications.2000.* p. 123.

As this chart illustrates, in the middle aged category – 45-64 years – people with an intellectual disability are four times more likely to be living in cared accommodation than any of the other disability categories. The reason for this disparity is likely to be a result of the ageing of their parents. Thus, as parents themselves age they become concerned about the future of their adult offspring, especially in terms of where they might live. Indeed, accommodation has been acknowledged as possibly the most critical issue for people with an intellectual disability as they age.

According to Bigby “the balance between people living in private homes in the community and in supported accommodation shifts from 70:30 in the 20 to 24 age group to 30:70 for the over-55 age group”.<sup>64</sup>

<sup>63</sup> AIHW, op.cit pp. 46-47.

<sup>64</sup> C. Bigby, *Ageing with a Lifelong Disability.* Jessica Kingsley, London 2004. p. 162.

In an earlier study, Bigby tracked 62 older adults<sup>65</sup> with an intellectual disability who were making the transition from parental care. In that study she found that immediately after they left parental care 61% were still living in a private home, 21% were living in an aged care facility and 18% were living in disability accommodation.<sup>66</sup> At the time of the study, which was on average 12 years after people had made the transition, some 65% were living in aged care facilities, 25% were in a private home and only 10% were still living in disability accommodation. Given that their average age at the time of the study was 65 years, the huge increase in those living in aged care facilities cannot solely be put down to advanced years. As we shall see, residential placement was a major theme in the interviews.

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<sup>65</sup> The average age was 52 years. C. Bigby, *Moving On Without Parents*. MacLennan & Petty, Sydney 2000. p. 82.

<sup>66</sup> *Ibid.* p. 84.

## **7. The interviews**

### **7.1 Individuals and their families**

A total of eight people were interviewed comprising two individuals, four parents and two siblings. All the names have been altered for this report.

Mary and John are the parents of Michael, who was not present at the interview. Michael has recently turned fifty and has also just recently moved into a Community Residential Unit (CRU). Whilst Mary and John were very pleased with the assistance they received from DHS in terms of the transition from home to a CRU for Michael they were very concerned that at the beginning staff at the CRU did not appear to accept that they might have expert knowledge about their son's health.

“One day I went over to take him some gear that he needed and one of the staff said he just screams and screams and screams. I said, well there must be something the matter and when he came home for the weekend he was screaming...and I realised he had pain.”

Mary and John were strongly of the opinion that CRUs needed to have a nurse attached to them who could administer medication when required. They were also highly critical of the policy of normalisation.

“the point is our kids aren't normal so how can you put them into normalisation. Now that is not being hard on the people who are disabled. It is saying that no one size fits everybody...The other thing the bureaucrats are saying is one house in a street with five people is an ideal 'normalisation'...What I am saying is, this model isolates them from the rest of the community.”

Janet is the mother of James. They have not lived together since he was a small boy and was taken from the country to Melbourne for his education. James is 56 and his mother is in her 70s. Janet feels very strongly that “the system is going backwards and this last 12 months, two years, the system has gone backwards, it has not gone forwards.”

James manages with the help of attendant carers who come in to help him in the mornings and at night. James lives by himself in a public housing unit. For him, his independence is the most important thing he has. He reported that he had had a couple of carers who had tried to get him to do things their way but he was able to get rid of them. Nevertheless, James is conscious that as he gets older he “can't move as much as I used to and my mates have moved on”. Thus, an increasing sense of isolation was expressed by both James and his mother. For James, this was a result of his lack of mobility as well as friends moving on; for Janet it was driven primarily by a lack of resources which curtailed James' ability to engage in outside activities.

Beatrice and her daughter Diana are aged 80 and 49 respectively. Diana has always lived at home with her parents and, until very recently, Beatrice undertook all the personal care required. She only reluctantly relinquished this role because of her age.

Now, Diana receives assistance in the morning and at night and on occasions when she needs to leave the house. Diana is also restricted to a wheelchair. Beatrice hopes that Diana's siblings will provide the care she needs when her parents can no longer do so.

Diana is a pioneer as she is in control of the resources she has available to spend on her needs. She prefers the new system of funding to the old one because of the high degree of control that it gives her. However, she has also found that there is a downside in that she has had to tell a carer that she did not want them to continue working with her. Diana said that what she looks for in a carer is "someone who sort of suits my personality". But she also found: "It's hard to get carers of the right type."

Although Diana has a circle of support, her family is quite reluctant to discuss where she might live in future. She has been put on the Statewide register for accommodation but her preference would be to live with a couple of friends.

Betty and Joan are the sisters of Fred who had been a long term resident of a CRU but, within the last year, he had been moved into residential aged care services. Prior to that, Fred had lived with his mother until her death in the late 1970s. Fred is now in his early 70s.

Both Betty and Joan were very upset at what had happened to their brother and they had deliberated for a long time before making contact with me because of how upset they were. They also did not want their brother to speak to me as they felt that he had only just settled into his nursing home and my questions about what had happened could only upset him.

Whilst living in the CRU Fred had worked in a nursery which was also part of the same service who provided his accommodation. However, Fred had been retired from working when he was in his 60s. Betty recalled that "he didn't like the fact that he couldn't go to work in the nursery".

In 2004 Fred was moved from the CRU where he lived with a number of other men who were all around his own age and whom he had known for more than twenty years into a nursing home.

Betty and Joan were angry about this move for a number of reasons. In the first instance, they felt that they should have been present when their brother was given an assessment by the Aged Care Assessment Service instead of being informed by telephone that the assessment had been done. Secondly, Betty and Joan were told they then had six weeks to find a nursing home for their brother. Although the agency gave them the name of someone who could help with placements, they did not find her particularly useful. Furthermore, they felt that the agency should have informed them that there was a cost involved.

Betty finally found a placement broker;

"who was cheaper and I said to my brother he is promising us that he will make sure that he finds a place for activities for Fred to be occupied during the day because of the wrench from not going to his day centre.

And I really believed him that he would find such a similar place because a lot of nursing homes, whether you like to admit it or not, they're drugged out of their minds. They just sit in their chairs and doze all day."

When asked what the impact of moving had been on their brother, Betty and Joan said he was "devastated. Fred didn't want to leave his friends, he cried many times". Fred is the only resident with an intellectual disability in the nursing home. Although Fred is not engaging in the same level of activities as he had been when living at the CRU and attending day activities specially geared towards older people with an intellectual disability, his sisters were very keen to say "don't put it down that we're unhappy. We have to accept things and make adjustments all round." At the same time:

"our main beef is the long association we've had with the agency. It's left a very bitter taste in our mouths... Their whole manner towards us, the way we were spoken to, the way we were treated as less than human beings, the stress we were under."

## **7.2 Disability service providers**

Altogether, some seven disability service providers were interviewed, although one provider did not wish to be recorded. One of those interviewed managed a unique government-funded service especially for people who are ageing with a disability. This worker reported that there was a bit of a mindset in some CRUs that "it's not their job to find them (the residents) day activities" which contributes to some of the difficulties around the issue of retirement from day programs for older people living in CRUs.

"Some people...are coming in unskilled and basically, if that's the culture of the house... But one house has this brilliant holistic approach and the program can work really well with them but around the corner, this other house...nup. We either come in and take this person out from 9 till 3 or the person can't stay at home. That's it."

In terms of the relationship between the disability and aged care sectors, this manager reported:

"I don't think the aged care sector is really well geared up to deal with what I think is going to be a fairly big influx... I think one of the things still is the big divide between disability services and the aged care sector. One example of that at the moment is we're supporting a woman in her late 80s who lives in an SRS and wants to remain living in the SRS. She has issues with incontinence and cannot afford continence products. And we've tried to go every where for funding. The aged care sector won't touch her because she's living in an SRS which is disability-funded and she's in a disability-funded thing so they won't provide her with any assistance around continence."

In relation to what happens, in her experience, to people who encounter the service system later on in life, she replied:

“...at a network meeting I was at this morning I heard that with ACAS assessments done with people with an intellectual disability, invariably the person will come out as high level regardless of their competencies...it’s not done through observation it’s done through Mum and the questions asked of Mum are can your daughter go to the toilet on her own? No, I have to do everything for her. Can your daughter help you in the kitchen? No I have to do everything for her. And in actual fact Mum has always done everything for her but she is actually quite capable of doing a whole lot of things.”

Another provider believed that whilst older people with an intellectual disability may be assessed as in need of nursing home care, finding a place could be extremely difficult.

“We’ve got contact with a broker who shops around, knows what people want, tries to find it in the local family area. We use her so that we can get the right place for that particular individual because access into aged care services for people with intellectual disabilities is very difficult...people with an intellectual disability often come with a reputation and because they’ve got an intellectual disability they might be more hard work...the reputation of having some behaviours, not always being able to look after themselves in their personal hygiene, so they come with different care needs.”

It’s not just that aged care staff might lack knowledge to work with older people with an intellectual disability, disability service providers themselves acknowledge that they require staff with experience also in aged care. As another provider said:

“I would love to have some staff with Certificate III in Aged Care...I think it gives them more knowledge as to what their needs are. I mean normally the Certificate IV in Disability it’s about independent living, you know, skill teaching, giving them dignity of risk and all that. But when you reach a certain age, yes you can still give them a little bit of dignity of risk but I think you need to take a little bit more care because their skill level is deteriorating...I think a care plan would be far more appropriate.”

When asked what might help her ageing clients to remain in the CRUs this provider suggested that funding needed to be provided for an active person on at night.

Another disability services provider believed that one of the major issues as people aged with an intellectual disability related to planning for the future, particularly planning for a time when parents are either themselves too old to care or are dead.

“...lots of the families that I’ve worked with, the long-term planning word is an extremely dirty word that you don’t bring up because that brings in, I suppose, a lot of fears and that thought of that they’re not going to be around forever, the carers.”

This inability to discuss the future was sometimes based upon earlier experience of the service system:

“Quite a lot of them that have had their son or daughter in CRUs prior have had really bad experiences...It’s kind of something they don’t want to consider again, even though at times it’s the only option for their son or daughter...I suppose they have felt that their care was inappropriate for their son or daughter or the place they were placed in wasn’t appropriate. Some of them have obtained injuries through where they were living in the supported accommodation...”

In terms of managing to obtain any aged care services for her clients in the disability area who are ageing, this provider said that she found it “really difficult because they’re falling in the gaps”.

“They have a disability so sometimes, at times, the aged care services don’t want to, I suppose, touch them...It’s not my area, it’s your area type of thing. But we have been successful in some cases.”

When asked who was best placed to provide services to this particular client group, the provider felt that “it’s a collaborative thing...There are some things that belong in the aged care sector and there are some things that belong in the disability sector. So, it’s really working together so that you can receive the best care for the client. So, it’s not about one or the other it’s actually about working together and finding out what’s best for the clients.”

### **7.3 Aged care service provider**

One aged care provider was interviewed for this project and she was with a facility that contained a younger woman with an intellectual disability who had been living in the low care residential facility since her late forties.

According to this provider, Emily’s care needs have not really changed since she arrived at the facility about 8 or 9 years earlier.

“...she’s got a problem with her hygiene, some parts of it, some parts of her planning, her depression. I think sometimes her loneliness, being bored because that’s the thing we needed to look at for her very closely. The companionship – she was always looking for somebody she could be close with.”

When asked whether she felt Emily was in an appropriate environment, she replied:

“That’s an interesting question. I’ve asked that question myself many times over because she goes to [an outside agency] where she does activities four days a week...So she does a great deal of things with that group and made great friendships there. And she’s being picked up and, of course, then she comes home and she does some work for us. But I often wondered if she would be better off in a house with friends her age...Not saying more of a disability, an intellectual disability, but her level of disability. I think she would cope better with that. Because she has often the feeling that she’s not accepted by the older people because she’s not fast enough in her own eyes.”

Even though this provider felt that the facility tried hard to accommodate Emily's needs this did pose difficulties for them.

“I think Emily wants to have constantly something and maybe that's because that's her disability that she needs to have a person around her. If not she will retreat into her own room and crawl under the blankets...We have things on in the evening, but not always and you cannot be with her every minute of the day.”

The potential for Emily to be lonely and somewhat isolated was something that exercised this provider greatly and caused her some worries.

“I really wish sometimes that Emily could have a close friend here, with her own type of disability...but, yeah, that hasn't happened over all those years. I mean we always encourage her to do things and go out with people and maybe that's also a good stimulation for her, to still go out with people who have no intellectual disability and they all love her.”

This provider's concern for Emily was not simply about providing the right environment, but also knowing whether they were able to provide her the necessary stimulation she required. In addition, Emily's behaviour – particularly her sexual behaviour – was not what the facility was used to. That is, it was not that residents could not engage in sexual activity, but in Emily's case they felt that they had to ensure she really understood what she doing, especially since the males she was getting involved with did not themselves have an intellectual disability. There were concerns, therefore, that Emily might be exploited.

#### **7.4 Policy workers**

The policy workers interviewed raised a number of key issues. For example, one of the workers felt that if individualised funding were properly implemented then there should be no barriers between disability and aged care services as the question as to who should provide the services would be determined solely by the actual care needs of the individual.

As this worker reported: “We overly structure the system into so many different programs that suck in a lot of extra administrative effort that is unnecessary, I think.”

“But if you really individualise the funding around a person's individual needs...they could stay home when they wanted to and they could go out when they wanted to...We force people from the CRU out to somewhere between 9 to 5...So it's not effectively a home. So, I think the idea of an ageing person...ageing at home was an accepted principle in the wider ageing community and yet there seems to be this funny notion that when old people [with an intellectual disability] want to stay at home it means they should be sent off, packed off to a nursing home.”

Another policy worker believes that the pressure to find supported accommodation to meet the demand may be encouraging providers to move their older clients into the residential aged care system.

“They shouldn’t have to be shunted along just because their support needs change or because someone else is trying to get in the front door. And that’s the real danger. It’s the same with the CRUs, you know. There’s a danger that people say ‘well if we pop this person across to a nursing home or even an aged care hostel, that’ll create a place where there’s people clamouring for these places. It’s not fair that this person should be taking up a place’.”

The question of retirement from attending day programs was another issue raised: “The other flexibility I should say is the Day Program stuff because I think that’s a major issue and, you know people do deserve to have a kind of retirement”. When told there were now day programs especially designed for older people this policy worker responded “So they don’t get retirement, they just get shifted to a different day program!”

The third policy worker interviewed had a longstanding interest in the needs of ageing carers. For her: “for many ageing carers the most significant issue is what happens when I’m too ill or unable to continue. And that concern is both about the need for appropriate supported accommodation or the wish for a service system that will support people in a less formal setting.”

For her, she had noticed a considerable difference between older and younger parents of children with an intellectual disability.

“I think the younger families are far more influenced by sort of rights ideology and the advocacy training that was available to them. I think carers who are currently ageing are likely to be a group of families who may have taken their son or daughter home against the advice of the prevailing medical wisdom and have struggled and fought for everything that their son or daughter has got...So they’ve had to battle for everything that they’ve got and I think ...among some ageing carers, there’s a sense that the community has let them down.”

In terms of how well the disability and aged care sectors worker together this worker remembered a time when she worked in the Department of Human Services and “we were trying to...one of agendas was trying to get the disability sector and the aged care sector to talk to each other and we had that one-off thing that had representatives of both sectors but I don’t know that it went anywhere. I think there’s been various attempts since and they’re still quite isolated.”

Part of the problem, as she saw it, was to do with their differing philosophical underpinnings. “You know if you compare the two Acts they are miles apart in terms of underlying philosophies”.

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