

**SUBMISSION TO THE SENATE INQUIRY INTO
PLANNING OPTIONS AND SERVICES FOR PEOPLE
AGEING WITH A DISABILITY**

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Opportunities for people with a disability

ENDEAVOUR FOUNDATION

The Endeavour Foundation (Endeavour) is one of the largest non-government organisations in Australia providing services to people with a disability and their families. Endeavour supports more than 3000 people with a disability through a mix of services and businesses, including accommodation, day and employment services at over 220 locations across Queensland & New South Wales.

While not-for-profit, Endeavour is also a public company limited by guarantee. Endeavour 'shareholders' are Endeavour Members. These Members comprise families of people with a disability as well as members of the broader community who want to be associated with an organisation that does great work with Australians who need support – a little or a lot – in their everyday lives.

ENDEAVOUR'S RESPONSE

Endeavour is committed to being a leader in responding well to People with a Disability who are Ageing (PwDA), and has been actively developing an Ageing Response Strategy over the past 12 months. This has been in response to the issue being the most frequently raised concern by family members, increasing unmet needs being raised by support staff, as well as to the broader population trend towards ageing. As a result, Endeavour has developed a Position Statement on Ageing (see Appendix A) which will direct future efforts in relation to this issue, and which forms part of this submission.

UNDERPINNING PRINCIPLES

Three fundamental principles underpin this submission. Endeavour contends that these should inform the Senate Committee's consideration of the issues:

- PwDA are in a double-jeopardy risk position of discrimination as a result of being prone to the negative stereotypes generally associated with disability and ageing (Janicki 2009, p.75)
- PwDA have the same right of access to services and other supports as those enjoyed by the general ageing population, in keeping with the principle of being supported to lead an ordinary life
- The same policy principles that are applied to the general ageing population should also be applied to PwDA, including Ageing in Place (Bigby 2010), Active Ageing and a Life Course approach (World Health Organisation 2002)

It is Endeavour's experience that these principles are markedly absent from current policies and practices impacting on the lives of PwDA.

RECOMMENDATION 1:

That the principles of:

- *Equity of access;*
- *The right to lead an ordinary life; and*
- *Ageing in Place, Active Ageing and a Life Course approach*

form the foundation on which future policy and program responses to the needs of PwDA are based.

THE AGEING ENDEAVOUR POPULATION

When identifying who constitutes the population of PwDA within Endeavour, two key factors are considered:

- The generally accepted opinion that the life expectancy of people with intellectual disability (*excepting people with Downs Syndrome and those with profound and multiple disabilities*) is now more similar to that of the general population (Janicki et al., 1999), and
- Endeavour’s experience that many of its service users have begun to demonstrate signs of ageing and associated increased care and support needs earlier than the ‘age 65 and over’ marker generally used in aged care policy and program development. This observation is in keeping with research showing that some PwD experience premature ageing (Webber et al 2006, p.1). It also mirrors the experience of Aboriginal and Torres Strait Islander peoples (ATSI), who share with PwDA the characteristic of poorer health (among others) that has contributed to Australian aged care planning being based on the number of ATSI people aged 50 years and over (Australian Institute of Health and Welfare [AIHW] 2009, p.86)

Of the total **3951** service users to whom Endeavour actively provides support services and supported employment, the following sub-groups have been identified as falling within the category of those facing issues associated with ageing:

TABLE 1: Endeavour Service Users Facing Issues Associated with Ageing

Age Group	Number of Service Users	% of Total Service Users
40 -49	1072	27%
50 - 59	765	19%
60 - 64	177	.04%
65+	88	.02%
TOTAL	2102	46.06%

As the people represented by these figures begin to exhibit signs of ageing, their needs increase and begin to incorporate ‘care’ as well as ‘support’ (Bigby 2010, p.11). While Endeavour is committed to responding to the changing needs of its service users, it is clear that in the absence of a clear policy framework and associated programs and funding sources, Endeavour’s capacity to provide on-going and appropriate support to these people is stretched and necessarily ad hoc.

RECOMMENDATION 2:

That the increasing longevity and premature ageing experienced by PwD be critical considerations in the development of relevant and appropriate policy and program responses.

ISSUES OF CONCERN

The remainder of this submission addresses the key areas of life for PwDA that Endeavour believes are being impeded by the current lack of relevant and clear policy direction. These areas of life are:

- access to current aged care programs, including appropriate assessment tools
- knowledge of ageing processes and appropriate responses
- transition to retirement
- ageing in place

ACCESS TO CURRENT AGED CARE PROGRAMS

As a prelude to this section, it should be stressed that Endeavour is not seeking placement in aged care for younger PWD, or pre-mature or inappropriate placement in aged care for PWD of any age. Rather, our focus is on the needs of those PWD who are experiencing increased care needs as a result of ageing phenomena.

PwDA face a number of discriminatory barriers in accessing current aged care programs due to 'not fitting' current models of service provision and funding.

At the program level it has been Endeavour's experience that PwDA do not encounter the equity of access to aged care programs enjoyed by the general population of ageing Australians. For example,

- Most people with a disability who receive state-based accommodation funding cannot simultaneously access Commonwealth aged care funding, such as Community Aged Care Packages, to meet their ageing-related needs.
- Currently, if a person aged under 65 years receives state (disability) support they are excluded from receiving additional support related to ageing.
- Current state disability programs do not adequately support people over the age of 65 as it is expected that they will access aged care programs. It is acknowledged that this is an area currently subject to COAG considerations.
- Often, PwDA experience an unwelcoming environment from both staff and residents in aged care services.
- Aged care agencies are not appropriately resourced or trained to respond effectively to the particular needs of PwDA.

Because of the discrimination experienced by PwDA in accessing aged care programs to meet their ageing needs, Endeavour supports the argument that there is a "pressing need for entry pathways into residential aged care (*& community aged care programs – added by Endeavour*) that differentiate between groups and which are not based on chronological age" (Webber et al, 2006, p.2).

In addition to the access barriers identified above, Endeavour's service users who are ageing also experience difficulty and inequity in accessing aged care services due to two factors related to the assessment for eligibility process, i.e., variable interpretations amongst Aged Care Assessment Services (ACAS/ACAT) of the aged care legislation in relation to access to assessment, and the lack of a validated assessment tool that accurately identifies increased support needs for PwDA.

When supporting its service users to be assessed for eligibility for aged care services, Endeavour's experience mirrors that found in the national study conducted in 2006, in that while "aged care legislation emphasises functional rather than chronological ageing. In practice, ACATs prefer not to assess people younger than 65–70 years, and certainly not to refer these younger people to residential aged care" (Fyffe et al 2007, p.7).

Endeavour's experience of accessing assessment for aged care also highlights the need for an objective, consistent and recognized assessment tool to be used with PwDA. Once again, this need is reflected in the same national study referred to above, whereby

ACATs reported difficulties in assessing people with disabilities referred because of issues of ageing. They referred to the unsuitability of standard assessment tools; the lack of sufficient consultation with people who know the history of the person with a lifelong disability; and the absence of previous records of functioning and assessments, which make it hard to differentiate ageing-related issues from disability-related issues (Fyffe et al 2007, p. 7).

RECOMMENDATION 3:

That future policy development reconceptualise the traditional boundaries and access to aged care based on chronological age, and considers the particular needs of different groups within the broader ageing population.

RECOMMENDATION 4:

That the Senate Inquiry support the piloting of an aged-care-in-the-home project by Endeavour, or similar organisation, to provide aged care support to PwD whose increasing support needs are due to ageing and are at risk of moving prematurely into residential aged care.

RECOMMENDATION 5:

That the Senate Inquiry supports the development of an objective, consistent and validated assessment tool to assess the changing needs of PwD as they age.

KNOWLEDGE OF AGEING PROCESSES

As mentioned above, Endeavour's experience is that PwDA often encounter an unwelcoming environment within aged care services that have limited knowledge and resources with which to support their specific needs. It is therefore imperative that aged care service providers (as well as disability support service providers) receive training and development in relation to the particular needs of PwD as they age. Endeavour's main priority in this regard is ensuring that mainstream aged care services are enabled to appropriately respond to the needs of PwDA.

There is evidence to support the fact that staff practice and attitudes produce more positive outcomes for this cohort than programs. Bigby (2005, p.84) found that "structural arrangements or programs models may be less important than the micro operationalisation of objectives". Further, Clement and Bigby (2008, p.iv) found that "staff activity and support is central to enhancing the 'quality of life' of people with intellectual disabilities".

Endeavour is advised that no similar training exists in Australia, and that knowledge of the particular needs of PwDA is widely acknowledged as being inadequate in both the aged care and

the disability sectors. Endeavour contends that there are many potential benefits from pursuing the development of training modules addressing this gap, including:

- staff may be better placed to work more effectively with PwDA within existing hours
- reduction of staff frustration and stress in relation to providing services to this cohort
- a valuable contribution to culture change within service provision to PwDA

RECOMMENDATION 6:

That the Senate Inquiry support the development of a comprehensive training and development program to ensure aged care and disability service providers have improved knowledge and understanding of the needs of PwD as they age.

TRANSITION TO RETIREMENT

Endeavour Foundation is the largest employer of people with a disability in Australia and provides employment for more than 1800 supported employees at 24 Australian Disability Enterprise (ADE) locations across Queensland and New South Wales.

In recent years, operational staff of Endeavour Disability Enterprises have consistently reported that a significant number of supported employees are ready to retire. In January 2010, management of Endeavour Disability Enterprises identified 227 supported employees for whom retirement is likely to be a more appropriate alternative to employment. This figure represents approximately 12% of all Endeavour supported employees.

Observations of operational staff are supported by research. For more than a decade, numerous studies and commentators have identified the urgent need to address the issue of retirement for people with a disability, and the need for pre-retirement planning and support (AIHW 2000; Lawrence and Roush 2008; Ashman et al 1995). It is estimated that, if programs are not developed to assist supported employees to retire, by 2018 approximately 46% of all Australian supported employees may be 'ready' for retirement (Donne 2008). However, many of these individuals will remain 'unretirable' because there are currently no day program alternatives supported employees can retire to, and no support provided to assist them in negotiating the transition from work to retirement.

This situation impacts significantly and negatively on stakeholders in several ways. Firstly, older people with a disability are disempowered, feeling too old or tired to work but without the resources or skills to search out other options. Operational staff of Disability Enterprises report that some ageing supported employees regularly arrive at work distressed; others' health and mobility have deteriorated to the point where they are no longer productive and/or, worse, can no longer work safely.

Secondly, younger people with a disability are prevented from entering the paid workforce because older employees, who would prefer to retire, are taking up limited places in Australian Disability Enterprises.

Also, the productivity and organisational viability of Disability Enterprises come under threat when a large proportion of supported employees demonstrate declining levels of productivity. Clearly, enabling retirement for supported employees is an issue requiring immediate attention.

Endeavour's focus is to provide opportunities for people with a disability to participate in the every day life of the community. Retirement is an 'ordinary experience' and a right for non-disabled people, yet many people with a disability cannot enjoy this right without support.

Endeavour has recently developed a *Transition to Retirement Program* in the form of a Demonstration Project to assist existing supported employees to transition from paid employment in Disability Enterprises to a retirement lifestyle. However, as Endeavour is not currently funded to facilitate retirement of supported employees, nor do operational staff currently have the resources, manpower or skills to implement this Program, additional Commonwealth funding is required to implement this initiative.

RECOMMENDATION 7:

That the Senate Enquiry support the piloting of a Transition to Retirement Program by Endeavour or similar organisation to ensure adequate and appropriate support to PwDA leave employment in a planned and supported way.

AGEING IN PLACE

It is acknowledged that the term 'ageing in place' can mean different processes and outcomes in different contexts, and requires clearer conceptualization for future policy development (Bigby 2010, p.11). In addition, as Williamson and Harvey (2007, p.8) suggest,

"It is important to note that the notion of 'ageing in place', in the broader sense, for some people with a disability is difficult to comprehend as socially people may have spent large parts of their lives displaced and isolated from community life."

For the purposes of this submission, Endeavour is calling for those principles which have underpinned policy direction in Australian aged care over the last 20 years to be equally applied to PwDA. Endeavour understands these principles to be:

- seeking to understand the preferences of the ageing person in terms of what 'home' and 'in place' means for them;
- ensuring that the family, social and service/support networks of the person are maintained to the greatest possible extent
- providing practical solutions such as home modifications where needed
- enabling adequate transition support and knowledge exchange for the person as they move to aged care services

RECOMMENDATION 8:

That the same principles underpinning ageing in place in Australian ageing policy also form the foundation on which future policy and program responses to the needs of PwDA are based.

APPENDIX 1**Endeavour Foundation Position Statement on Ageing**

The Position Statement on Ageing outlines the principles guiding Endeavour Foundation's work on addressing issues of ageing for people with a disability. For a more in-depth discussion of each principle, please read the Explanatory Notes.

1. Endeavour will support people with a disability to age in ways similar to those experienced by the general population.
2. Endeavour will support people with a disability to understand what it means to grow older.
3. Endeavour supports the principle of Ageing in Place for people with a disability.
4. Endeavour supports Active Ageing for people with a disability.
5. Endeavour supports a Life Course approach to good health for people with a disability in preparation for an optimal lifestyle in later life.
6. Endeavour will support people with a disability to undertake planning appropriate to each life stage, including retirement and end-of-life planning.
7. Endeavour will provide information to the primary carers of people with a disability who are ageing to locate resources and services that can support them in their caring roles and assist them with planning for the future.
8. Endeavour will provide operational staff with appropriate training to enable them to respond well to people with a disability who are ageing.
9. Responses to individuals with a disability whose needs are changing due to ageing will be coordinated across Endeavour services.
10. Endeavour will support people with a disability who are ageing to connect with mainstream resources, programs and services in order to comprehensively meet their changing needs.
11. When the needs of a person with a disability exceed the services Endeavour is able to reasonably deliver, the organisation will assist the person and his/her family to relocate to a service better suited to meeting his/her needs.
12. Endeavour will continue pursuing partnerships with government, non-government organisations, and the business sector to implement models and strategies that address ageing for people with a disability.
13. Endeavour will continue to advocate to government and non-government organisations for appropriate policy and systems development, resources, programs and service responses for people with a disability whose needs are changing due to ageing.
14. Endeavour will respond to the changing needs of people with a disability who are ageing as a disability service provider.

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