

Submission to the  
Senate Community Affairs  
References Committee

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

On Behalf of the Mai Wel Group

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## **1) Executive Summary**

This submission details the inadequacies of the current system in regards to planning options and services for people who are ageing with a disability.

The areas identified are the ones in need of improvement in order to provide and maintain a high quality of life for people ageing with a disability.

The main areas focussed on will be:

- the need for more options within the disabled community;
- the need for a smooth transition process between different programs;
- more places within current programs and
- more flexibility for program users.
- more effective distribution of programs and funding.

There are several recommendations which arise out of these identified inadequacies. These include:

- co-operation and communication between state and federal government;
- effective strategies to fully determine the actual need in the community so programs can be adjusted accordingly, and
- redistribution and faster processing of funds.

## **2) Introduction**

The Mai Wel Group is in an excellent position to identify and address these needs. Since 1960 they have been dedicated to protecting the rights of people living with a disability and ensuring that they experience a high quality of life by providing them with education and work opportunities.

Because Mai Wel has been operational since 1960 and often retains clients for many years, they are well-placed to identify the current short-comings of the system in regards to people who are ageing, dealing with ageing carers and whose support needs may be increasing.

The Mai Wel website (2010) directly identifies these needs with the statement “The organization must find strategies to further address the changing needs of supported employees, residents and clients who are ageing and in need of quality retirement options.”

Of particular importance in regards to the planning options and services available for people ageing with a disability is the transition process between one program and another. Without a structured system which ensures a streamlined process for people accessing services, people in need will continue to miss out. Not being able to access appropriate services in a timely fashion is perhaps the biggest issue facing people ageing with a disability and their elderly carers.

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This submission was compiled after an interview with two Mai Wel Executive Managers and the author would like to thank Margaret Haskal and Lucy Crawford for their contribution.

### **3) Identified Inadequacies**

#### **3.1 Lack of transition process**

It has been observed at Mai Wel that the transition from one program to another within the disability service industry is sufficiently hard as to constitute a significant obstacle to many people. Currently, the situation appears to be that participation with one program may negate your eligibility for another. An example given by one Mai Wel interviewee is of the difficulties facing people who are ageing within the Australian Disability Enterprises, or ADEs. In explanation:

“the way our government funds some of our programs for people with a disability makes the retirement process difficult too and I know, a good example, something that was very positive that was introduced just recently, its called ‘Life Choices’ and ‘Active Ageing Program’... unfortunately one of the conditions for eligibility for that program is that you can’t be working in an ADE for more than 8 hours per week.”

It has been observed that a person working in supported employment, or an ADE, has little incentive to risk their place in one program when there is no guarantee that they will be accepted into a more suitable one.

In this particular example, the eligibility clause is the mechanism preventing a smooth transition from one program to another but in many cases it is complicated by movement between government levels.

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The situation at the moment is that day programs are funded by the state government, while ADEs receive federal funding. Because day programs are more suitable for someone who is ageing, (although that is not their primary function), this is seen as the natural progression from an ADE. Unfortunately, it means that the state government has the potential to be overloaded with people unable to stay at home or remain in ADEs. In regards to moving between state programs and federal programs, one interviewee remarked: “That is the biggest problem.”

Similar submissions in the past have denoted the same issue as an obstacle to access and maintaining a high quality of life. A 2003 paper by the NSW Industry Group on People Ageing with a Disability states that “Program guidelines and funding streams do not allow for flexibility and portability of funding. Funded programs are frequently captured within Commonwealth, State and Departmental boundaries. It is difficult for people to seamlessly transfer from one funded program to another.”

What was also identified was the lack of ‘stepping stones’ between significantly different programs, as well as between home care and supported accommodation, which can make the transition difficult and should be incorporated into future planning options.

It has been observed by Mai Wel that “the direction that we would like to go is that smooth transition between federally funded and state funded services because without that smooth transition we can’t see a great deal of future.” Not being able to transition from one program to another is a huge obstacle which needs to be addressed if people ageing with a disability are to be presented with effective choices.

### **3.2 Lack of Choice**

There is an identified lack of choice in regards to suitable programs and accommodation for people ageing with a disability.

People with a disability find it difficult to gain access to generic aged services, especially given that the Australian population overall is ageing.

Lack of effective choice means that people are remaining in ADEs longer than they may necessarily want to because there are no available programs, or no spots available in current programs. One Mai Wel interviewee says it is a case of recognising the importance of choice:

“we can talk about all the choices in the world and you can have the best transition plan in the world too but at the end of the day if there is no placement out there in a day program for you, well, and you’re living at home with ageing carers and mum and dad just couldn’t look after you for 24/7 then effectively there is no choice really. Choice is only good if you’ve got alternatives.”



Another scenario applies to people with a disability living in a group home. These homes aren't normally funded for 24 hour support so if a resident wishes to retire, they must be able to enter a day program or similar program as they cannot be left at home unsupported

Even if a place within a day program is found, programs such as 'Active Ageing' only cater for 55-64 year olds. From the age of 65, it appears as if options are reduced dramatically and this issue of 'declining care' should be addressed. Often the only model people have in their minds when contemplating possible retirement or living arrangements in old age is the 'group home' or 'supported accommodation' model.

Mai Wel offers alternative models which can extend the carer role and these include: the Intentional Community Model, which takes the focus off of paid care and places it on a supportive community environment. This would go some way in ensuring support for the disabled person after the primary carer has died. Models such as the 'shared care' model can also extend the life of the caring role and allows people with a disability to build independent living skills.

### **3.3 Lack of flexibility within current programs**

Current programs can be extended to service more people if some of the guidelines within which it operates could be tailored to suit individual needs.

Using again as an example 'Life Choices' and 'Active Ageing', these programs offer 18 hours service per week. A participant may only want to be involved with a program for eight or ten hours a week, but is forced to take the full 18 hours as a condition of participation. By allowing people to take only 'part' of a program where suitable, this frees up 'extra' hours which can be given to others in need.

Such an approach would potentially mean that more people are serviced for effectively the same funding.

Making programs more flexible with their allocation of hours would allow current resources to be used to their fullest potential, and service the maximum number of people possible.

Research needs to be conducted into how many people would be happy with only 'part' of a program (a reduced number of hours) and how much support a disabled person who is ageing needs in a typical week.

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The Mai Wel Group

It is important for organizations like Mai Wel to know how numbers such as '18 hours' are reached by the government and what support needs these numbers are based on.

### **3.4 Funding and Distribution Inadequacies**

Although more options and alternatives are certainly needed, there are funding issues and unequal distribution of current programs which also need to be addressed.

One of the problems associated with funding is that it appears to be based on the program and not the person; someone may be in a program for the majority of their adult life and the funding would remain the same. Obviously, this does not take into account the changing needs associated with the ageing process.

Applications for new funding take a long time to be processed; one interviewee remarks "the funding doesn't change, there's no process to be capturing change and support need." Having a funding system more reflective of support needs would assist in maintaining a high quality of life as people enter old age.

Once allocated, it is difficult to change the funding in a timely manner. Gathering evidence of change can be a long and costly process with costs incurred being the service providers responsibility with no guarantee that additional funding will be granted. Often service providers (many of whom are not for profit organizations) are left to find the funds to respond.

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Mai Wel's assertion that funding should be more closely associated with the needs of the person (as opposed to the program) is reinforced again by the 2005 Catholic Social Services Victoria submission, where an observation was made that "if individualised funding was properly implemented then there should be no barriers between disability and aged care services as the question of as to who should provide the services would be determined solely by the actual care needs of the individual." (Leveratt, Bowers and Webber, 2005).

In a similar vein, there is an inequity amongst the different programs on offer which means that people with the exact same support needs are often stuck in older, less well-funded programs.

It was observed by Mai Wel that people in 'blocked day' programs do not receive as much support as someone in the newer 'Active Ageing' program: "They are in the same situation, ageing carers, living at home with ageing carers, so that there is an inequity between the new programs and the old programs. That's something – that really does need to be addressed."

### **3.5 Insufficient identification of needs.**

If realistic planning services and options for people with a disability are to be formulated, it is essential to fully identify the level of need within the community.

Lack of comprehensive information often means that the options available within the disability service industry do not meet the level of need. This can be a case of both insufficient funding of current programs and lack of choice.

One interviewee at Mai Wel suggests that this is where a 'case managed' model could help to bring about attention to the level of need: "it is hard to determine the real level of need and do any planning for future need when there are so many 'hidden' people with a disability and carers out there. At the moment people generally have a case manager allocated when the situation reaches crisis. This is difficult for all concerned to manage. A pro-active rather than reactive approach is needed."

Without adequate research, it is impossible to know how many people within the disabled community are currently facing old age and retirement without suitable options. In regards to ADHC, one Mai Wel interviewee states "They don't know how many people are out there, either ready or looking to move into service."

It is difficult for ADHC to know how many ageing people want/need a day program. A draft vacancy management system is currently being looked at by ADHC which will manage vacancies in existing day programs but will not capture people with a disability who are ageing and working in an ADE and wanting a day program or who are in the general community and find navigating the service system difficult.

What we do know is that the demand for day programs far out ways the supply. This is evidence by the number of clients applying for Life Choices and Active Ageing who were unable to secure a place.

The submission by Catholic Social Services Victoria (2005) compiled a list of actual needs experienced by people ageing with a disability; this list identifies what needs exist but not the percentage of people within the community experiencing them. The list includes (but is not limited to):

- A high need for formal support services, particularly accommodation.
- A high need for age-appropriate day activity and leisure programs.
- A high need for assistance in choosing, locating, negotiating access and travelling to community-based programs.
- May need special assistance in personal financial planning.
- Reassessment of needs should be available.

One of the ways suggested of doing this involved having every person with a disability being case managed by someone from ADHC or a similar service, much like the Community Support Teams that are operating currently.

This idea has many advantages: case management would identify the deficiencies within the system, and people with a disability would have someone to advocate on their behalf.

It should be said, however, the case management model would only be truly effective if case workers are able to provide their clients with effective and accessible options.

Some people with a disability are actually 'over-serviced', having access to two or three different programs, as anomalous as this may seem with previous arguments about lack of access and an inability to transition between programs.

If the government can identify the areas of deficits, where people are not being serviced at all, they can redress the balance and ensure a consistency which would help people feel secure within the system.

#### **4) Conclusion**

By having a smooth transition process from one program to another, access to planning options and services on behalf of people ageing with a disability is increased.

This transition process can be facilitated by having good communication between different levels of government and a more comprehensive understanding of funding differences.

It is also vital to have a range of effective, accessible alternatives so that people are not forced to remain in unsuitable programs.

Information is essential in better understanding how programs and funds can be more effectively distributed, an avenue which should be explored before further funding is committed.



## **5) Recommendations**

**Recommendation 1: That the Committee facilitates co-operation and communication between the state and federal government in regards to transitioning between programs.**

**Recommendation 2: That the Committee explores other models to complement supported accommodation and provide people with choice and that there is a re evaluation of program distribution to ensure equal access.**

**Recommendation 3: That programs which can feasibly do so are restructured to allow people to use only part of the program and thereby extend resources.**

**Recommendation 4: That the Committee makes the creation of a more flexible funding process a high priority.**

**Recommendation 5: That the Government, in conjunction with the Department of Ageing, Disability and Home Care and other relevant state bodies explore and commit to an effective strategy to properly identify levels of need within the community.**

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