SENATE INQUIRY INTO PLANNING OPTIONS AND SERVICES FOR PEOPLE AGEING WITH A DISABILITY

SUBMISSION BY THE CENTRE FOR CEREBRAL PALSY (TCCP)

Background

On November 25 2009 the Senate referred the following matter to the Community Affairs Reference Committee for Inquiry and report by 2 September 2010 :

> Access to planning options and services for people with a disability to ensure their continued quality of life as they and their carers age, and to identify any inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers.

The Committee is seeking written submissions from interested individuals and organizations to assist them with the Inquiry. This submission has been prepared for this purpose.

Australian Population Trends that impact on Disability and Ageing

The Australian Bureau of Statistics (ABS) estimates that Australia's population, which is 22 million, will grow to between 30.9 million and 42.5 million in 2056. A combination of low levels of fertility and mortality rates over a sustained period of time, and increasing life expectancy at birth has resulted in major changes to the age composition of Australia's population. In 2007 people aged 65 years and over made up 13 per cent of Australia's population, however in 2056 this figure is projected to increase to approximately 25 percent. The rate of increase in this age group is estimated to peak in the next ten years as the majority of the baby boomers reach retirement age. Between 1997 and 2051 the number of people aged 75 and over is estimated to increase by about 3.5 times. At the same time the number of people aged 85 and over is estimated to increase 5.3 times from 216,000 in 1997 to about 1.1 million in 2051. The proportion of this category as part of all people aged 65 and over will increase from 9.6 per cent in 1997 to 19 per cent in 2051.

Ageing trends in the population tend to increase the prevalence of disability because the risk of disability is always greater in the older age groups as demonstrated by the 2003 ABS Survey of Disability, Ageing and Carers (SDAC). The survey found that one in five people (3,958,300 or 20.0 per cent) reported a disability and that a further 4,149,000 or 21 per cent of the population had a long-term health condition that did not necessarily limit their everyday activities. It also estimated that 1,238,600 people or 6.3 per cent of the population experienced disabilities with a 'profound or severe core activity limitation' in that they always, or sometimes, needed assistance with self-care, mobility or communication. Just over half of people over 60 years reported a disability (51 per cent) with 19 per cent having a profound or severe core-activity limitation.

Western Australian Population Trends that impact on Disability and Ageing

The number of people with disabilities in Western Australia has increased from 355,500 in 1998 to 405,500 in 2003. The estimated number of people with profound or severe core activity limitation increased from 101,400 in 1998 to 115,800 in 2003. Over the 20-year period from 2006–2026, it is estimated that most of the increase in the numbers of Western Australians with disabilities will be due to population ageing. The number of older Western Australians with disabilities will increase substantially as the ‘baby boomers’ gets older. It is estimated that there will be an overall increase of 115.7 per cent of people with disability who are 65 years, from 136,700 in 2006 to 294,800 in 2026. The annual rate of increase is estimated to be 3.9 per cent.

The under 65 years of age cohort with profound or severe limitation is expected to grow by 14 per cent over the 15 years. By comparison the increase in people 65 years and over with a profound or severe core activity limitation disability is expected to be a massive 85 per cent.

This means that about 100,000 senior Western Australians will need considerable personal care and assistance every day. In addition about another 200,000 people with disabilities aged over 65 will have restrictions on mobility, functioning behaviour, communications, cognition, and employment as a consequence of their birth or acquired disability.

Person-centred Care Options

The Centre notes the several aged care measures announced by the Minister for Health in the past week and congratulates the Government on these measures. While acknowledging the usefulness of these measures for the aged care sector, the Centre urges the Government to urgently address the needs of people with disability who are ageing or have acquired a disability as part of the ageing process. It should be noted that the needs of people without disabilities who are ageing are considerably different to the needs of those who have a disability and are ageing.

Over the years the policy shift both federally and from a State perspective has been for people with disability and older people to live in their homes and in their own space or communities. This shift is reflected in the number of clients moving away from institutionalized settings, including group homes, into more community oriented living, the availability of a number of home support services, individualised care packages and by this philosophy being enshrined in the Age Care Act. Nevertheless, a sizeable majority of older Australians with disability continue to have limited options available to them to pursue planning options that enable them to achieve their personalised goals and aspirations.

Person-centred care option is the tool upon which independent living is based. Elements of person centred planning are that the person is at the centre and is consulted through the planning process; the person chooses who to involve in the process with family members and friends partners in the plan; the person chooses the setting and timings of meetings and the plan refects what is important to the person, their capacities and the support they require; there is shared understanding amongst all people involved that the person is the expert and that the plan results in action about life, not just services; It reflects what is possible rather than what is available.

In Western Australia, research undertaken by the Centre for Research into Disability and Society over a two and a half year period demonstrates the success of personalised residential support for adults with developmental disabilities and their families. This research nullifies some of the traditional views held, namely that person-centred living cannot be achieved for people with high or complex needs; or that people with disability need to live together to achieve a sense of community.

The range of accommodation currently facilitated through the Centre provides greater scope for people with cerebral palsy to live independently, to have some degree of choice and to enable them to be active participants in community life. However, limited resources and economies of scale place restrictions on the level of independence, empowerment, autonomy, and the resultant level of community participation these clients achieve. Availability of and access to services rather than actual choice or need of an individual usually dictate the development and participation of clients' programs. The programs being offered are not unique to an individual, which is a critical element for person-centred care options. Even where these services are managed and delivered with a high level of professionalism they fall short of being unique to an individual person. To enable clients to have choice it is critically important that they and their families have access to a range of planning and service options. Person centred individualised options will also enable individuals and their families to engage in longer term planning, a capacity that is currently limited.

Therefore planning of services needs to be made on individual assessments supported by a variety of service programs which cut across usually traditional divides to best accommodate individual needs and circumstances. The Inquiry is urged to make the philosophy of person-centred care options the cornerstone upon which the planning and delivery of services is made.

The Need to Assess the Changing Nature of Services

Access to planning options will be meaningless if the options are not backed by appropriate services capable of fulfilling the plans. Currently, the lack of services has been a primary drawback for the practise of person-centred living options lagging behind the philosophy.

The statistics provided above indicate that although there is a spread of people with disabilities in all age groups, there is now a heavier concentration of people with disabilities in the 65 years and over age group. Given the increase in the proportion of this age group with disabilities, the likelihood is that there would be a change in the nature of services being demanded. The needs of people who have early onset disability and experience early ageing are likely to be different to those who experience a disability as a result of the ageing process. Both groups will experience a range of biological, psychological and social needs. While the needs of both groups in some aspects would be similar, in other aspects their needs can be vastly different.

It would be imperative for a major focus of the Inquiry to be on the changing needs of services required including the ability of clients to transfer between the various types of services due to their changing circumstances. The balance between specialist services and generic services, or between employment support and day activity services, or those between physical support services and emotional support services, or between acute care versus more generalised forms of care, would need to be carefully assessed. This would be particularly important for people with cerebral palsy where the ageing process can commence early, but where life expectancy has increased due to better therapeutic and technological advances. For clients who age prematurely, age care services are not the most suitable option. Currently, the disability services sector appears to be unable to care for clients with early onset ageing who tend to be referred around between services.

In terms of specific services, the availability of a variety of accommodation options, increase in the available mental health services as well as improvements in the quality of these services, and services relating to the transition from work to retirement is critical. If person-centred care options are to become a reality it is necessary to ensure that specially designed housing to accommodate a variety of equipment and supports vital for people with disability be made available. Universal design has not come into its own as yet. To enable buildings, products and environments that everyone can use safely and effectively, the principles of universal design needs to be applied to both private and public housing as well as to the surrounding community.

For many people with disabilities employment also provides the social constructs of their daily operation. For this reason people with disability tend to continue working even when their option of choice might be retirement. When they confront retirement, they also confront anxiety related to loneliness and loss. The gaps that currently exist in the transition to retirement phase needs to be addressed urgently to ensure a constructive retirement for people with disabilities. Making social participation grants available to the non-government sector to establish programs to address this gap needs to be considered as a matter of urgency.

It is clear that determining the balance in the nature of services required will not be easy, particularly because the client group is not homogeneous. They are diverse not only in age, sex, location and ethnicity but also in their disabilities and the level of support required, all of which contribute to the range of services required.

Services for Aboriginal People, People from Culturally and Linguistically Diverse (CaLD) Backgrounds and People in Rural and Remote Locations.

TCCP is very aware of the limited services available to Aboriginal people and people from culturally and linguistically diverse sections of the population. The need for specifically targeting services to these groups intensifies with an ageing population traditionally reluctant to access available services for a variety of reasons including suspicion of service providers, lack of information, and services not being conducive to their lifestyle and circumstances. It is also the case that people are more prone to becoming relatively more ethno-specific as they age, thus becoming more reluctant to access available mainstream services.

The incidence of disability in the Indigenous community of Western Australia is estimated to be consistently higher than for the non-Indigenous population. Despite Indigenous people comprising 3.8 per cent of the State's population, Aboriginal children made up 8.4 per cent of children born with cerebral palsy between 1980 and 1999. It is also suggested that Aboriginal people were twice as likely as their non-Indigenous counterparts to require assistance with a core activity. It is also the case that Aboriginal people have a different understanding of 'disability' to that of the mainstream. Having a disability does not separate people from the rest, with people with disabilities accepting kinship roles and responsibilities. These aspects of Aboriginal culture augur well for genuine partnership between them and service providers to ensure service/program effectiveness. However, to enable Aboriginal clients and clients from CaLD backgrounds to access mainstream services it is vital for these services to make every effort to raise their cultural competence. While many services are making some effort to do so they appear to be restricted to staff in the metropolitan area which is insufficient, particularly in the case of Aboriginal clients. Increasing the role of advocacy services working alongside mainstream services may be one option that needs to be explored.

Anecdotal evidence suggests that many families from CaLD backgrounds in need of assistance have little knowledge of the availability of services. The lack of fluency in English is another factor restricting their use of services. Unlike in the case of Aboriginal clients, interpreters in most CaLD languages are available, although the frequency of use is restricted due to associated costs. A factor of greater concern among many CaLD communities is the tendency amongst them to keep issues associated with disability hidden. There is an expectation within CaLD communities that families would provide for their family members with disabilities at all times and in all circumstances. Placing elderly relatives in accommodation outside the family home can be considered a shameful act, hence the Inquiry should consider providing support to family carers supporting older disabled people at home.

In this context of both groups of clients, the provision of services in an environment that is familiar to them is likely to achieve the best outcomes. The gap in services that seems to exist in the delivery of appropriate services for Indigenous and CaLD clients suggests that the Inquiry should give some priority to the intersection of disability and ethnicity in considering the planning and delivery of future services.

The hidden population with disabilities in rural areas is well known. Equally well known is the lack of services in rural and remote areas. Many people with disabilities in rural areas have been and are being cared for by parents and other members of families. With many informal carers ageing, the care of people with disabilities in the rural areas needs immediate attention.

Interface between aged care services and disability services

While there are separate services to cater to the needs of seniors and for people with disability, there are several concerns surrounding the interface between the two services. Some of the major difficulties are:

- Transition from one type of service to the other. As people with disabilities age and contemplate moving from disability services to aged care services one of the main challenges they encounter is that the funding provided to aged care services can be lower and clients are not able to access a proportion of both types of funding. Although the base rates for Disability Support Pension (DSP) and Age Pension (AP) is the same , clients transferring from DSP to AP may, by losing some entitlements such as

mobility allowance and incentive allowance which they have been getting over a long period of time, be less well off.
- People with disabilities on supported employment have little opportunity to have access to a reasonable superannuation scheme because the 9 per cent superannuation guarantee is calculated on top up earnings they make, rather than both the top up earnings as well as the DSP which they receive for supported employment.
- Some types of disability increase the likelihood of early onset ageing and would require aged care services whilst still continuing to receive disability support. Scope for this is currently limited. Clients with cerebral palsy can fit into this category.
- Some of the people with disabilities who have coped with the support of families would need to obtain more formal support with ageing and with carers ageing but find it challenging to get into the disabilities support loop.
- Each system appears to have its different histories, traditions and customs, administrations, funding bases and operating cultures which makes it difficult for clients to navigate across them.

The Centre urges the Inquiry to give due consideration to the national Disability Insurance Scheme about which the Prime Minister recently released a statement. Adopting such a scheme would be a forward thinking, indeed, landmark reform of the sector likely to be effective, equitable and efficient. Such a scheme is particularly important in view of those ageing carers, who may pass away or become too fragile to care for a family member, risking family members becoming isolated. It would be expected that an insurance scheme will enable funds to be more equitably distributed and to provide a major boost to the quality of care a majority of clients currently obtain through case management facilitating independence and long-term planning and service provision. The Insurance scheme will enable a continuum of care, minimising the stop-start approach to care that clients are forced to currently endure because of the manner in which disability and aged care services are organised.

It is generally known that traditionally disability services are not well equipped to manage the conditions and symptoms of ageing anymore than aged care can meet the specific disability services. Given the nature of the clients, it is critical that these two service areas work to cut out the silo mentality and artificial boundaries they erect around themselves and work in partnership for the benefit of the clients. It is no longer possible to have artificial factors such as age-based criteria to determine service responsibility. As stated before, people with disabilities can experience conditions arising from premature ageing despite not reaching the traditional age upon which ageing is said to commence. If transferring processes need to be maintained between the two types of service providers it is essential that they be made transparent and easily manoeuvrable. It is also the case that when people with disabilities age they may confront grey areas of service, not being clear which services are most suitable to their needs or not having services available that do meet their needs. They might also require aspects of a variety of services rather than a single service that would meet their needs. This would require more frequent transferring between services.

It is important that service transition not be solely or primarily age driven. To make this the case in an ageing population would cause more and more people to wrestle the system and go without required services at least in the short to medium term. An artificial age barrier also provides an ‘out’ for service providers to decline services to clients in need of care, making them some-one else’s problem. It is also the case that when age is used as the major criterion families can be split by being clients of two different sectors. Staff working in these agencies must be trained and empowered to adopt a flexible approach to service provision to enhance opportunities for clients’ individualised goals and needs to be met.

The Centre is aware of situations when clients have fallen through cracks in the system, missing out on the care they require because an artificial age boundary has been reached within the disability sector. Most potential retirees with disabilities are not well informed about services available to them after retirement. Services should be funded to provide this information to enable the retirees to be well prepared and maximise the available opportunities. There is little doubt that if this type of programs are funded that the transition to retirement for people participating in ADEs and DESs would be a lot smoother. These programs will assist to reduce anxiety and enable clients to find a clear direction for their retirement. It would also reduce the amount of people with a disability who retire from supported employment without the necessary medical, financial and personal supports.

The Submission provides three case studies of supported employees who found the transition to retirement difficult for a variety of reasons.

Case Study 1

Supported Employee with Cerebral Palsy and an intellectual disability at an Australian Disability Enterprise (ADE) decided to retire when he was 55 years of age after being a supported employee for 38 years. He believed that he was entitled to $30,000.00 from Government at retirement despite being advised otherwise by ADE. Although he had worked at the ADE for 38 years his superannuation was small because the actual wages he received over above the disability pension was between $ 4000 and $ 5000 per year and superannuation is only paid on the top-up payment when they were eligible. Contact with was made by ADE on his behalf to government departments for additional support to enable him to enjoy his retirement. However, no additional support was made available to him. The Disability Services Commission of Western Australia invited him to make use of their Local Area Coordinators such as filling forms but this was not the type of support he required. Compounding the issues he confronted was that he was a diabetic that regularly suffered from hypoglycaemia. Once he was found by a person known to him in a coma on the side of a road. Being with the ADE for 38 years his entire social involvement was and continues to be with it.

The individual keeps in regular contact with the ADE, Seeking assistance as required. The ADE is not funded to provide this support but continues to support him because other avenues of support are not accessible to him.

Case Study 2

Supported employee with Cerebral Palsy and very high physical support needs decided to retire from an Australian Disability Enterprise (ADE) due to failing health.

The person was keen to transfer to an Alternative to Employment (ATE) service for 3 days a week and then retire from work. An application was submitted for state funding to attend an ATE several times over an 18 month period and was declined on each occasion. Support to make the transition from work to retirement was not available to him.

The individual was forced to retire from employment because of ill health and passed away 2 weeks later, never having an opportunity to enjoy any aspect of retirement. He kept working for as long as he possibly could, even though his preference after 41 years of work was to retire before he eventually did and enjoy his retirement.

Case Study 3

After working fat an Australian Disability Enterprise for 40 years a supported employee with Cerebral Palsy was thinking of retiring for a number of years. At age 65 feeling physically drained due to decreasing mobility the individual retired from the ADE.

He had participated in a retirement program trial conducted by The Centre for Cerebral Palsy and the ADE on its own initiative 12 months prior to retiring. During this trial the individual identified participation in a lawn bowls club to be his preferred activity after retirement. A visit was organised to a club when he realised that he could not access many of the facilities. As a result he lost interest in lawn bowls. This was an important decision for the individual as he had built his retirement dreams around participating in a lawn bowls club including attending functions.

The trial retirement program then provided him the opportunity to change his focus to public speaking. His focus was to tell people about being a person with a disability in the community. With the support of the ADE and TCCP the individual did get opportunities to speak about being a person with a disability and how best to support people with disabilities by becoming involved in the TCCP orientation program.

From this experience and with support from the ADE he was nominated for a seat on a Government Disability Council where he was recently re-elected to sit for a further 2 years.

Although the trial program was completed successfully, owing to the inability to attract funds the program did not continue.

Staffing

The Centre acknowledges the difficulty of acquiring qualified staff in both sectors, but particularly in the aged care sector and sees training as a critical component to increase the availability of staff and more appropriately skill staff already in the system. To enable a strong partnership between the two service sectors, the National Industry Skills Training Council should be urged that training packages be geared to ensuring that workers in both sectors have knowledge and understanding of both ageing and disability. Salaries should also be reflective of the vulnerability of the client group and the importance of the work to society. Without this the sectors will continue to struggle to attract the quality of staff that the clients deserve and also that strong governance and safety requires.

Superannuation Guarantee

The Inquiry is urged to consider recommending that clients on DSP transferring to Age care pension not lose the additional allowances they have access to when they do transfer. In addition the Inquiry is urged to recommend that the 9 per cent superannuation guarantee be calculated on the actual earnings as well as the DSP for all on supported employment. This will also ensure that all supported employees are eligible for superannuation and not only those that received a wage of $450 or more per month.

Support for carers

One in eight Australians provide care to those needing assistance due to disability, old age or chronic illness. In 2005 these carers were estimated to have provided 1.2 billion hours of care. It is estimated that the age group where the number of carers would increase would be in the 65 and over age category. The projection is for carers in the 65years and over age category to increase by an estimated 110 per cent between 2001 and 2031. Projected figures also show that by 2031 carers aged 65 and over would comprise 56 per cent of all carers. Over the next thirty years the number of carers is projected to rise by 57 per cent while the number of aged people needing care will rise by 160 per cent. Against this backdrop it is imperative that the Inquiry focus strongly on the integral role of carers.

In terms of population numbers, the Australian Institute of Health and Welfare estimates that in 1998 over 711,000 people 65 and over were living at home with unpaid carers providing support, either with or without support from formal services, compared to only 127,900 people living in residential aged care and 8,800 receiving Community Aged Care Packages. Support from carers ranged from occasional assistance to 24 hour care. In economic terms, Access Economics estimated that if all hours of informal care were replaced with services purchased from formal care providers and provided in the home, the replacement value would be $30.5 billion. This figure does not factor in the personal costs to the individual carers such as the burden of pain and suffering associated with depression, musculoskeletal injuries and other problems. In contrast, the Government's expenditure on aged care in and Home and Community Care was less than a third of that total. Recognising the important and major role of informal carers, Government have for some time provided them some support through welfare support payments and service provision although the level of support remains comparatively lower than for other streams of care.

The estimates are that over the next thirty years there will be a declining ratio of carers to the number of older people needing care. Currently, the heavy reliance on informal care by family and friends as the major component of our community care system shows that planning ahead is critical over the longer term to manage the situation and avoid a crisis in care. In determining directions and priorities it would be particularly important for the inquiry to give significant consideration to the nature and extent of supplementary support and services to sustain the care situation because of the substantial commitment and costs that care giving carries. It cannot be assumed in policy making that informal care from family and friends will be available for people needing care in the same manner as has been the case to date.

There is anecdotal evidence which suggests that many carers have limited access to good information and are unaware of the available support including the carer's allowance. It is imperative that the relevant agencies make a concerted effort to make good information available to carers by using several means of communication. Currently, there is a tendency on the part of government departments to primarily provide information electronically. In the case of many of these clients, this method of communication may not be the most favoured. Innovative methods of communication would need to be developed to ensure that information reaches those who would most benefit from it.

Conclusion

The Centre looks forward to the outcome of the Inquiry to enable service providers to more effectively provide services to a rapidly increasing client group. The submission highlights the need for the philosophy of person-centred care to be reinforced by making the philosophy the cornerstone of its directional approach. Such a stance will enable older clients to remain in their homes and communities for as long as possible with access to a range of services they can choose to fulfil their goals and aspiration. Equally, the Centre strongly endorses the need for the appropriate balance of services to be available for a client group that is diverse and for aged care services and disability services to work in tandem to ensure flexibility in services provision likely to be required by many clients. Greater recognition and support to carers is critical to ensure that this valuable resource is sustained.

Judy Hogben
Chief Executive Officer
The Centre for Cerebral Palsy
106 Bradford Street
COOLBINIA WA 6050
Ph: 08 9443 0211
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