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Committee Secretary
Senate Community Affairs References Committee
PO Box 6100
Parliament House
CANBERRA ACT 2600

Dear Sir/Madam

The Tasmanian Government welcomes the opportunity to contribute to the Senate inquiry into planning options for people ageing with a disability.

While the Tasmanian Government is implementing substantial reforms to the provision of Disability Services in the State, there is a need for mainstream services to acknowledge and respond to the increasing needs of people ageing with a disability. Facilitating partnerships between specialist and mainstream services across the three levels of government and non-government organisations, and the development of personal transition planning will be integral to delivering successful options for people ageing with a disability.

Please find enclosed the Tasmanian Government's submission and thank you again for the opportunity to comment.

Yours faithfully

David Bartlett MP
Premier



Submission by the Tasmanian
Government

Senate Standing Committee on
Community Affairs

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

June 2010



Tasmania
Explore the possibilities

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

Introduction

Australia, and Tasmania in particular, has an ageing population which has important implications for planning now and into the future. Population projections indicate a greater number of older people requiring support and assistance and fewer people of working age to support them. While the overall disability rate in Australia was estimated to be 20 per cent in 2003, the prevalence of disability is strongly related to age, with rates of disability reaching 81 per cent for those aged 85 years and over¹.

As the proportion of Tasmania's population aged over 65 increases, so does the number of people with a disability, including those with a severe or profound disability. In 2003 in Tasmania 48 per cent of the population aged 65-74 years, 63 per cent aged 75-85 years, and 73 per cent over 85 years of age had some form of disability². Four per cent of men and six per cent of women aged over 60 years in Tasmania also reported they had disability that caused core activity limitations, that is in communication, mobility and self care³.

Growth in the number of older Tasmanians will result in significant growth in the population of Tasmanians with a disability. The increased longevity of those with a disability will also contribute to the growth in demand for disability services. For example, people with lifelong disability acquire the same age-related disabilities (including dementia and musculo-skeletal disabilities) that affect other people and this increases their support needs as they age.

For people who have lived with disability all or most of their lives there are additional challenges associated with ageing. They are likely to approach their older years from a very different position and with very different financial, emotional and psychological resources.

In addition there is recognition Australia-wide of significant issues facing older carers. Many informal carers are aged 65 and over. As these people age and become less able to provide this care, or may require care themselves, there is likely to be an increased demand for specialist services.

Contemporary practice in disability services focuses on increasing the accessibility and responsiveness of mainstream health and human services. Facilitating partnerships with aged care providers and providing personal transition planning to people with a disability aids the transition process and reduces the potential risk of specialist disability services duplicating universally available services.

The national reform priorities under the National Disability Agreement (NDA) contribute to, or measure progress towards, people with disability and their carers having an enhanced quality of life and being able to participate as valued members of the community.

For a person with a disability, their family and carers, planning for ageing is critical to ensure that support arrangements can be put in place long before the need actually arises.

¹ Australian Bureau of Statistics, 2003 Survey of Disability, Ageing and Carers, Cat No 4446.0

² Australian Bureau of Statistics, Disability Ageing and Carers, Summary of Findings – State Tables for Tasmania, 2003, Cat No 4430.0

³ Australian Bureau of Statistics, Disability, Ageing and Carers, Australia: Disability and Long Term Health Conditions 2003, Cat No. 4430.0

All people should have the opportunity and support to choose where they live as they age. Many are choosing to remain in their own places until later in life, rather than move to traditional age care facilities. For people with disability, it is critical that support is matched to the needs of the person, rather than to the services provided by the facility in which the person is living. This enables a person who chooses to age-in-place to do so with similar aged care mechanisms and supports as the wider community. As people age, then the increased levels of specialist care and support needed should be negotiated between disability service providers and the person, their family and carers.

One of the identified priority areas for national effort through the NDA is older carers. Under the NDA project the focus will broaden from just older carers to include other specific target groups and it is now proposed that the work be included in the project being done by the Commonwealth to develop a National Carer Strategy. Other national efforts include work on early intervention and prevention, lifelong planning and increasing independence and social participation strategies.

The social and policy environment

The task of making appropriate preparation and planning for the future wellbeing of Tasmanians with a disability occurs in a context which is characterised by the factors listed below:

- The changed role of governments in respect of the provision and/or funding of disability support services, including a greater role for non-government organisations in delivering services;
- Viability issues for small community based services that impact on their capacity to continue to operate. However, it is just such services that many individuals and families prefer as they are perceived as being more able to know and serve people in a personalised way;
- Increased expectancy of choice and a fulfilled lifestyle by people with lifelong disability and their families;
- Lessening of extended family supports within society;
- Financial constraints including cost of living, effects of inflation on allowances and pensions, and reduced outside earnings;
- Indications that compensation funds awarded to those with an acquired disability may run out while the person is still alive;
- The constraints on the supply and availability of affordable housing;
- Viability issues for both smaller and larger organisations has meant that access to a support service is restricted to those people who have secured an Adult Lifestyle funding package from the Commonwealth Government. A limited number of these are allocated each year;
- Lack of clarity and understanding regarding how formal services and informal supports could best work together;
- Lack of readily available assistance to families to plan for the future support of their family member; and
- Conflicts of interest between ageing parents and their family members with a disability.

The concept of successful ageing for people with a disability and supporting their needs requires further development. There are a number of possibilities for approaching the development of support programs that could be explored further as listed below:

- Adapting disability services to the needs of older people with a disability;
- Developing specialist services for ageing people with a disability;
- Including older people with disabilities in generic or mainstream services for the elderly;
- Private, personalised arrangements which are financially supported through the utilisation of funding packages or private resources; and
- Utilisation of community capacity, including generic associations, clubs or programs to include and support people ageing with a disability.

National Reform

In April 2010, Tasmania signed up to the Council of Australian Governments' agreement on the establishment of a National Health and Hospitals Network (NHHN). This agreement includes the Commonwealth taking on full funding and policy responsibility for primary health care and aged care services, which are critical for people ageing with a disability.

The NHHN reforms will also result in a clear split of responsibilities for disability services and aged care. This disability/aged care split will see state/territory governments responsible for the services for all persons with a disability up to 65 years of age, and the Commonwealth Government responsible for persons aged 65 years and over, including those with disability.

Tasmania is actively working with the Commonwealth and the other states and territories to ensure a smooth transition. For example, the implementation arrangements for the reform will need to consider how the Commonwealth Government will provide a seamless transition in services for a person in Tasmania receiving disability services that turns 65 and becomes an aged care client.

Tasmania is currently ahead of the national average in the proportion of people with a disability 'accessing state/territory delivered disability support services' (22.8 per cent in Tasmania versus the national average of 20 per cent).⁴ The Tasmanian Government would like to ensure that this level of access to services is maintained post implementation of the NHHN reforms and that older Tasmanians with a disability are not disadvantaged upon turning 65 years of age.

Tasmanian Reform

Much of the national reform work under the NDA complements the work being done in Tasmania as part of the substantial reform agenda of Disability Services within the Department of Health and Human Services.

The Operational Framework for Disability Services (February 2009)⁵ is the document on which Disability Services System reform in Tasmania is being based. The Framework provides a clear direction for the future of Disability Services, which aligns with contemporary practices and supports increased responsiveness to the needs of people with disability.

⁴ COAG Reform Council National Disability Agreement: Baseline performance report for 2008-09, page 124, accessed via http://www.coag.gov.au/crc/docs/national_disability_agreement_report_vol1.pdf

⁵ Accessed via: http://www.dhhs.tas.gov.au/future_communities/reform_implementation_unit/disability_services_reform/operational_framework_for_disability_services

The Framework, which is being implemented over three years, promotes self directed planning for people with a disability, ensuring the services and supports available align with the goals and aspirations of the individual. For this to be effective a flexible continuum of supports must be available and often this means a mix of service responses (informal, universal, secondary and specialist options).

Reform actions and activities underway in Tasmania include:

- Implementing a new model for disability services which will be accessed through Gateway Services from July 2010;
- Using a common assessment instrument to ensure that access to services for people with a disability is fair and equitable;
- A project nearing completion on the complex and difficult process of establishing a 'unit price' per hour for delivering different service types; and
- Consideration of recommendations from a project looking at innovative ways in which day services can be delivered so that people with disability have more choice and control over their daily lives. This project investigated linkages between residential and day services, determining ways to best serve the needs of a variety of clients of different ages and how to provide smaller more specialised services.

Tasmania is also undertaking a review of the *Disability Services Act 1992* and the Community Equipment Scheme, both of which will affect people with disability who are ageing.

Issues

This part of the submission discusses the issues faced by people with disability who are ageing in Tasmania. The needs of adults with disability who are getting older are many and varied and include the need to be seen and treated as an individual with aspirations for personal growth, activity and experience.

Ageing carers

Tasmanian carers (both formal and informal) play an important role in providing daily care and support to people with disability and provide a significant social and economic contribution to society. It is critical that carers have the support they need and that the people they care for have the right mix of services and programs in place. In Tasmania the population is ageing faster than in other parts of Australia so it is even more critical for carers in this State.

Ageing without family

Vulnerable people without family or who have become disconnected from their family are without a likely source of support and advocacy. As a result they will, typically, be in a more precarious situation than those who are well connected with their family. Parents, generally, are concerned with the welfare of their children regardless of age and can play a role in planning and providing for their child's future well-being. Without family to advocate and/or plan for them a person is less likely to receive a tailored response.

Importance of allies

Those who have other allies such as friends, citizen advocates or paid advocates are potentially better supported than those who do not. Challenges for the service systems in working with the allies of people include: how to share knowledge in the interests of the vulnerable party; how to include allies in planning service delivery in respect of the person; and how to respond when allies raise issues of concern on behalf of the vulnerable person.

Provision of mainstream aged care services

In Tasmania, units within the Department of Health and Human Services work together to make sure that home and community care services and disability services are provided appropriately to the people who have the greatest priority. Disability Services, Home and Community Care and the Aged Care Assessment Team are three separate units that work together to provide a cooperative approach to support independent living, where it is possible and practicable.

Implementation of the new disability/aged care policy split under the NHHN reforms will need to consider existing cooperative arrangements like those noted above to ensure that the new responsibility split does not detrimentally affect service provision. Potential impacts to existing non-government organisations that provide integrated services will need to be similarly considered.

Appropriate services for people who are ageing in group homes

Tasmania has not been included in the national pilot for provision of aged care services to people with disabilities living in group homes. However, the State looks forward to the results of the pilot and to accessing this service arrangement in the future.

Retirement from day services and work

This is an issue for people with disability who do not have other support services to enable them to stay at home during the day. A national pilot for transition to retirement for older Australian Disability Enterprise workers is underway through the Department of Families, Housing, Community Services and Indigenous Affairs. Tasmania is not included in this pilot but looks forward to being involved in an expanded program in the future.

Appropriate accommodation for people with disability

The policy of ageing-in-place recognises that people with a disability should have the opportunity and support to choose where they live as they age. For people with a disability the advantages of ageing in place might include less disruption and continuity of care in a familiar environment. For service providers the challenges are greater and might include requirements of a different staffing mix, extra staff requirements and consequential cost increases, building upgrades and/or redevelopment costs.

A related project implemented in Tasmania is the Young People In Residential Aged Care (YPIRAC) project. During the first stage of the project, consultations with younger people with a disability living in aged care facilities revealed that some individuals did not want to move out of this accommodation as it meant leaving their community because no other suitable accommodation was available nearby. This is linked with the following discussion on rural and remote challenges. Fortunately the YPIRAC program has been able to provide many of those people living in Residential Aged Care with Enhancement Packages to improve their life styles in that accommodation setting.

Challenges for rural and remote areas

Tasmania also has a number of rural and remote areas where delivery of disability services is challenged by sector capacity. This is largely due to the lack of a local workforce and lack of numbers of people with disability needing support to form a critical mass for delivery of services.

Effective Transition Planning

Under the new Gateways system, people with a disability will receive an initial screening which will direct them either towards community services or to a Targeted Disability Assessment to determine their more specific needs. Once a person with disability is assessed as eligible then a process of long term planning for their future will begin and continue while they receive support through the disability sector.

Planning for the future

It is important that lifestyle decisions for citizens who are ageing with a disability are not left to chance, as the foresight to prepare and plan for the well being of a vulnerable individual is critically important. This preparation is best done on a case by case basis.

For most ageing parents contemplating an unknown, uncertain future for their vulnerable family member can be frightening. Good preparation for the future requires parents to balance their own needs and desires with the rights and needs of their adult child. Some parents may be more concerned with permanency and protection rather than the increasing independence of their son/daughter in the post-parental phase. In this sense, parental plans may tend to be conservative in nature. This raises ethical questions of the legitimacy of parents determining the future course of their middle-aged family member's life.

In practical terms parents may lack the necessary information and access to opportunities to learn about possible options in respect of supported living arrangements for their son or daughter. There may be a need for support to families to investigate possibilities.

Conclusion

The number of people ageing with a disability is increasing and due to the high vulnerabilities of these individuals, there is a need for leadership and vision.

While the Tasmanian Government is implementing substantial reforms to the provision of Disability Services in the State, there is a need for mainstream services to continue to acknowledge and respond to the increasing needs of this group. Facilitating partnerships between specialist and mainstream services across levels of government and non-government organisations, and the development of personal transition planning will be integral to delivering successful options for people ageing with a disability.

Further, the implementation of those aspects of the NHHN reforms that deal with the provision of primary, aged and residential care services (including the new disability/aged care responsibility split), will also be highly relevant to ensuring appropriate services are available for people ageing with disability. The transition arrangements to the new funding and policy responsibilities will need to ensure that the level of services currently available in states and territories will be maintained and improved over time.