

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

BEDFORD SUBMISSION - MAY 2010

BEDFORD

The Bedford Group is one of South Australia's leading and best known community service organisations, providing a diverse range of vocational and non-vocational services to over 3,000 South Australians with a disability or disadvantage.

This year Bedford celebrates its 65th anniversary of creating a brighter future for people with a disability.

Bedford's services for people with a disability cover a spectrum of activities, including supported and community based (open) employment and job search programmes, training, housing and accommodation, as well as day options services for those not able to undertake any form of employment.

Bedford's client profile is similarly diverse, including from the perspectives of types and differing levels of disability and age profiles.

In recent years, we have noticed an increasing trend with the average age of our employees and of the numbers who are over 40yo in our supported employment (Australian Disability Enterprise) workforce. Bedford now has 42% of its employees over 40yo and 21% over 50yo, figures which are consistent with those of the 2007 Disability Census and which we understand are aligned with research being undertaken into retirement in the disability sector - with predictions that these ratios will continue to rise over time.

Through these activities and demographics, not only are we involved in actual service delivery and implementation of Government policy, but we have come to develop an appreciation of many issues confronted by people with a disability who are ageing and/or their carers and family members - relating to needs, aspects of programmes which work well and not so well, and gaps in the system.

In preparing our response, we have also drawn on comments and observations from a number of resources, consultative mechanisms (including views of our Family Network group, a regular consultative and information sharing forum between family members and Bedford management) and projects in which we have been involved; the latter includes involvement in a 2009 study undertaken by Dr C Ellison et al, "Avoiding Institutional Outcomes for Older Adults with a Disability", as well as an internal project which explored the level of understanding of supported employees with a disability into the concept of retirement.

Bedford welcomes the growing recognition by Government and the community at large, of the implications associated with the changes to an ageing population, including those people ageing with a disability.

However, we believe that there are still a number of key issues that must be addressed to ensure a better future for people ageing with a disability. These matters are elaborated upon in our submission, and include:

- The Government policy context, including the interface between Commonwealth and State Governments, as well as across various Government portfolios
- Funding regimes – portability, the move towards individualised planning/funding models, enhancement to Disability Trust arrangements
- Enhanced access to information and resources
- General issues and strategies to address changes to one's circumstances with ageing - including retirement, ageing in place, criteria for residential aged care, and universal design.
- The overall service delivery context, embracing such issues as workforce development, technology and unmet need.

INTRODUCTION/BACKGROUND

In recent years, there has been a growing realisation across Governments and the community at large, of the changing profile and associated implications regarding an ageing population.

One sub set of this overall profile relates to people with a disability who are ageing, the focus of this Inquiry.

Furthermore, the AIHW 2009 Report into Australia Welfare suggests that the present 705,000 people aged 65 and over and living with severe or profound core activity limitations will more than double over the next two decades, a trend which if realised, will create additional pressures on a system which is generally felt to require enhancement.

Of further concern to the SA environment is the prediction by Carers SA that 56% of carers will be over 65yo by the year 2031 (Carers SA, Carer Awareness Campaign paper, State Election 2010). This will surely place even greater strains on support frameworks in years to come.

Various reports and pieces of research have referred to a number of barriers that impact on services designed to meet the needs of people ageing with a disability - some relate to legislation and policy; others are systemic; while a number are based on historical, community/societal or ideological factors. Carers and families experience similar limitations and constraints.

One commonly made observation is that it is sometimes difficult to locate and secure suitable support arrangements, not only within but also as a result of the interaction between Commonwealth and State programmes.

It is generally accepted that the prevalence of disability increases as people age, while certain types of disability also increase with ageing. Such factors may lead to a disconnect between groups of people requiring support and the very nature of Government programmes designed to assist these people.

As people with disability age, they are increasingly likely to require services from disability and aged perspectives and/or sectors.

The 2000 AIHW report, "Disability and Ageing", highlighted various groups as unlikely to be able to access appropriate services to meet their needs through the ageing: disability interface, including those with an early onset disability who have minimal living skills; people ageing with disability acquired during adulthood who have greater support needs as they age; and people with an intellectual disability who become frail, need increasing health care and may acquire dementia.

The Report also referred to the difficulty likely to be faced by people with a disability retiring from Commonwealth - funded employment programmes.

While there has been general recognition of some problems, such as the need for more streamlined and effective systems and inter-service linkages and the need to address the inappropriate use of some aged care services for younger people with a disability, overall progress has been slow.

It should also be noted that there are many people with a disability and their families who want to maintain their present family interactions and relationships but need appropriate support and assistance. Indeed, a 2002 AIHW report into "Unmet needs for disability services" highlighted a number of pertinent concerns relating to transitional arrangements, potential feelings of guilt about not continuing to support family members and the need for flexible services and supports.

The AIHW report also reflected that funds were primarily used to respond to crises situations and minimal longer term planning took place.

Much of the above is consistent with views expressed by a number of parents and carers of Bedford's Family Network group. One member highlighted concerns relating to "no planning [is] in place as for many, the future is unknown we are constantly told there is nowhere to go and no suitable accommodation no support or information [from Government] only help for 3 months in a crisis ..."

Bedford is keen to see how the recent National Health and Hospitals Network Agreement impacts on people ageing with disability, with the Commonwealth broadly assuming responsibility for community care services and specialist disability services under the National Disability Agreement for people aged 65 years and over and the States assuming like responsibilities for those under the age of 65 years.

Implementation of this reform will need to be carefully managed, to ensure all users of the system achieve desired outcomes. However, should it prove effective, it may provide insight into ways to best progress disability and aged care interactions and better meet the needs of people ageing with a disability and their loved ones/carers.

IMPROVING PLANNING OPTIONS

Bedford believes that there are a number of actions that need to be considered by the Inquiry, which will lead to improved planning options and services for people ageing with a disability.

The 2009 research project by Dr C Ellison et al ("Avoiding Institutional Outcomes for Older Adults Living with Disability") noted several recommendations with which we would concur, in particular:

- The need for clarification of jurisdictional responsibility for funding and service provision for people with a disability as they get older;
- Removal of barriers that create a perception that accessing disability and aged care services concurrently constitutes "double dipping";
- Consideration of special factors and differing individual needs of people ageing with a disability;
- Greater consumer participation in service design and delivery coordination;
- Increased education and a single source of information about service options;
- Workforce strategies to enhance staff competencies; and
- Greater cross sector collaboration.

Government Policy Context

The Australian Government's adoption of the UN Convention on the Rights of Persons with Disabilities; development of a National Disability Strategy and Social Inclusion Agenda; and consideration of a Long Term Care and Support (National Disability Insurance) Scheme are welcomed.

Not only do such measures reflect a commitment to a review and potential reform of disability service delivery in Australia, but they also serve to demonstrate the breadth of impact of disability issues on economic, employment, health, housing, social and human rights frameworks.

Nonetheless, Bedford believes there are a number of specific Government policy issues that should be addressed within the Inquiry's activities.

Models and Choice

Bedford is committed to principles that people with a disability should be able to exercise choice, make informed decisions about their lives and participate in community life as they see fit.

However, at times, Government policy constructs, associated resource constraints and views on disability service provision are seen to unduly impact on such rights; some people with a disability live in the community facing social isolation and have limited participation in community activities.

Some Bedford Family Network members have pointed to an apparent inconsistency in the way that different policies are applied and/or associated models of accommodation are viewed by Government – for disability and associated supported accommodation, a larger group of residents may not be considered appropriate; while for aged care, the approach is justified.

Others have highlighted shortcomings with certain models and frameworks for various other reasons eg concerns over isolation, non involvement in community activities, community resentment, and lack of required support.

Bedford has increased its community housing portfolio in recent years. However, we have also come to recognise that there may be a need for an appropriate form of larger accommodation settings for some people with a disability, including those who are ageing. Such a model could well enable residents with greater needs to live safely, have their needs met, access community services and participate in community activities in a way they feel comfortable.

As is the case with people in the general community, individuals with a disability will choose to live their lives in different ways, including with regard to their choice of accommodation/housing.

We also understand that the present system does not always cater well with regard to respite arrangements, in particular, in meeting the needs of ageing parents who have assumed primary care roles for their family members with a disability.

Based on the above, we believe a review should be undertaken of Government policy regarding the nature and scope of accommodation models which best meet the needs of people ageing with a disability and which observe general Human Rights principles and like Standards - rather than rely on a framework that focuses on smaller settings in the community where needs may not be adequately met, and integration and participation may be stifled.

Improved Government responses to changing support needs

The support needs of people with disability usually increase as they age. The history of some Government programmes suggests that responses to such changes are often problematic. One case in point has been the way that mental health issues have generally been addressed over the years; also, the lack of suitable accommodation and support mechanisms saw a number of people with a disability inappropriately housed in aged care facilities.

It is important that all levels of Government and of all persuasions work co - operatively to ensure programmes are appropriate, meet the needs of clients, and are well coordinated and seamless. The roll out of responsibilities under the National Health and Hospitals Network Agreement will be a useful indicator, and may set the framework as to how various jurisdictions and agencies within jurisdictions can best work with each other to meet desired outcomes.

We would maintain that the roles and associated responsibilities of all tiers of Government be agreed and clearly articulated to achieve the above results.

Cross Jurisdictional and Portfolio Funding

Over the years, difficulties have arisen in allowing the seamless transition of people with a disability from one jurisdiction to another and indeed, between different portfolios within the same tier of Government. Examples to demonstrate such limitations include people being able to access and utilise supported and open employment services concurrently; in the movement of people from day activity services to employment options; school to work transitions; and between disability and aged care services.

The correlation between ageing and disability highlights the need for the interface between disability, health, aged care, transport and other community services to be easier for people ageing with a disability

People must be able to access the most appropriate support from the most appropriate provider, regardless of whether that provider is part of the aged care or disability sector, or a combination of both. At present, that is problematic.

It is questionable whether the system will truly provide the degree of flexibility required to meet needs unless there is greater scope for portability of funding and movement of people across different portfolios and jurisdictions, to cater for changing needs. Such an approach will enhance the use and appropriateness of more individualised planning options and choices for people ageing with a disability.

It is also recognised that the third tier of Government viz Local, has an important role to play in the provision of community based supports for people with a disability, for the ageing population, and for those people with a disability who are ageing.

Additional resources, infrastructure and support will be necessary to ensure Local Government agencies are well placed to support and provide relevant activities to cater for the increasing and changing disability/ageing demographic.

Review age criteria for people inappropriately housed in residential aged care

Governments' initiative to reduce the number of inappropriate placements in residential aged care is welcomed, but focuses on those under 50 years of age.

Bedford recommends that consideration be given to the age criterion being 65 years, an age more aligned to other programme and agreement criteria.

Funding Regimes

There are a number of issues which have impacted, are impacting, and will likely impact on the funding frameworks for people ageing with a disability.

A better co-ordinated, appropriately funded system

There are significant levels of unmet need for services across the nation. A greater level of investment and a more robust approach to service provision is urgently needed.

Bedford welcomes the Inquiry into a long term care and support system (National Disability Insurance Scheme). We will be lodging a submission in support of such an initiative.

It is imperative that all tiers of Governments agree and support a funding mechanism that guarantees lifetime support and care for people with disability, including those who are ageing with disability.

Increased use of individualised planning

Individualised or person-centred planning has gained momentum as a means of enhancing the quality and appropriate control of services for people with a disability.

Under this approach, support is tailored to fit the individual, rather than the opposite - having the individual fit into a defined system model. Such an approach assists meet the changing support needs of the person with a disability, allowing flexibility to help the person achieve their goals and lead a more enriched life.

The adoption of this approach across Commonwealth and State programmes is seen as an ideal way of improving an individual's capacity to plan for the future.

The development of a system which could allow portability of such funding across jurisdictions would further enhance its value.

When considering planning options, it would also be prudent to ensure that the system has sufficient and appropriate resources/providers to meet any specific needs of people ageing with a disability.

Enhance special Disability Trusts

Bedford acknowledges the intent behind such trusts and a subsequent intent to improve these to better assist families make future provision for their children. However, while a Senate Inquiry made a number of recommendations to enhance this initiative, minimal actions appear to have occurred.

Members of Bedford's Family Network have expressed interest in the concept and potential of Disability Trust arrangements to meet their loved ones' longer term needs, but have found aspects of the framework limiting.

Bedford would encourage Government to progress other recommendations of the Senate Inquiry, particularly the scope of reasonable care and accommodation; beneficiary eligibility requirements for people with an intellectual disability or mental illness; and additional assistance to families to establish and maintain Trusts, including low cost legal and financial advice and access to planning services.

Improved information and resources

As people with a disability are living longer, additional resources and supports are needed to help these people, and their carers and families, address the myriad of planning tasks involved. Some such activities are complex, may be difficult to navigate and can be emotionally draining on those involved.

It is important that there is relevant and easily understood information about the scope of Government programmes and various support arrangements, especially for those who have not used the service system to any extent.

The need for a mix of general disability and specific disability information should be considered in this regard, to ensure that any issues, needs or resources particular to a given disability grouping eg mental health, intellectual, autism, are available.

One Bedford Family Network member (parent of a person with a disability) highlighted difficulties experienced by some people with intellectual or cognitive impairments, like her son, who have difficulty in understanding information in various documents, survey questions and the like. This parent alluded to increasing difficulties as her son ages.

Further, the development and availability of information and resources needs to be considered from more of a “whole of life” perspective, with earlier and more timely interventions– this will assist people with a disability and their carers/families with longer term planning, and help to reduce the likelihood of crisis situations later in life.

Resources should also consider respite and emergency care, as well as longer term support arrangements.

One parent noted the difficulty experienced in locating services for his son; on occasions, literally stumbling on to relevant facilities and benefits eg through friends, discovering “entitle[ment] to a carers allowance[able to] get home help through his local council”. This parent also noted “it is very hard for the uninitiated in disability to know what to do or where to go for help”; he queried whether a “one stop shop” where information on a range of disability issues to cover one’s life cycle, might be possible.

The preceding view was similarly expressed by another parent, who articulated there was “the need for access to give information and support when needed ... information for parents and carers at every stage of life”.

We are aware that the South Australian Government has developed a web based framework along such lines, with a life cycle approach used to categorise information. .

While in its formative stages, and with more work needed to enhance its ease of use and scope of material, it may serve as a template from which a more encompassing and rigorous system/portal might be developed, supported by the “one stop shop” as described above for those not comfortable with (or unable to access) a technology based system, and with appropriate hard copy material also available.

General Issues and Strategies to address changing circumstances with ageing

Ageing in Place

It is important that future planning takes into account the overall benefits likely from people being supported to live in their own home and “age in place” - not just in terms of economic considerations but also from social, personal satisfaction and choice perspectives. Cost factors should not be the sole determinant to move older people with disability from community living arrangements to residential aged care.

There are also restrictions on the ability of supported accommodation residents to access certain community care services to enable them to age in place in their existing accommodation.

It is important that any such limitations be reviewed and amended to allow these residents to age in place in their existing homes/residences.

Consideration of the alternative housing/accommodation models as described earlier, should be incorporated in any such review.

It should also be recognised that as people age in place, the system needs to ensure that adequate “third party” resources are available, as carers and family members will similarly be ageing and less able to offer the levels of support that they may have in their earlier years. This applies to both short term (respite) and longer term arrangements.

Ensure universal design standards are applied

While some progress has been made, more needs to be done to ensure there are improvements in access to buildings of all types, public transport and general community activities and services.

It is important that design takes account of the needs of people with a disability who are ageing with regard to adaptive technology, aids and equipment, as the needs of this cohort are likely to increase as they grow older.

Government must ensure the necessary infrastructure and funding support is available and part of longer term planning considerations.

Improve retirement options for people supported by disability employment services

The number of people with a disability who may retire from work is already significant and is predicted to grow in coming years with an ageing workforce in many organisations.

A number of employees with a disability face the dilemma of what to do once they are confronted with retirement.

For many such people, work is not merely a form of income generation and meaningful activity or contribution to society, it forms part of their support structures, social networking and relationships.

Unfortunately, there are not always State-based services available to meet the needs of people as they retire.

It is imperative that the system takes account of and provides additional and meaningful activities and funding to support people moving from employment settings, arguably through Local Government programmes, to allow for the ongoing social interaction and participation of people with a disability as they age.

It is also acknowledged that there may be like considerations for people ageing with a disability who are involved in non vocational Day Option/Activity programmes.

Improve access to appropriate respite services

Feedback from Bedford Family Network members and carers indicates that access to respite is very important, sometimes a necessity.

The availability of respite should be strengthened, with the process concurrently streamlined and simplified, to ensure family members and carers receive flexible and responsive support with a minimum of fuss.

It should also be noted that respite services must also be delivered in a manner which supports the interests and wishes of the person with disability.

Respite services will therefore, need to take account of this dual needs focus - the needs of the person with a disability and the needs of the family member/carer.

Service Delivery Context

Aged care and disability service workforce issues

The changing demographics and needs of people ageing with a disability, and of the interface between disability and aged care sectors, will increase pressure on the workforces of both disability and aged care providers.

Workers from both sectors will need to expand their skill bases and understanding of emerging issues for clients, including with regard to specific disability issues eg mental health, intellectual.

It is therefore recommended that in exploring planning and service options, consideration should be given to means by which staff competencies might be enhanced, how existing training programmes might be modified and how aged and disability roles might best interact from an industrial relations perspective.

There is also a need for Government to recognise that the community sector, embracing aged care and disability, has not always been able to compete with other parts of the Australian economy with regard to remuneration and benefits for its staff workforce; the sector's focus has been primarily and rightly on service delivery to those in need.

In this regard we are conscious of potential flow on implications for the sector resultant from the award modernisation process and pay equity case.

This has implications in terms of strategies to enable and support service providers to attract and retain staff, as well as the additional imposts involved in safety and quality standards compliance for the sector.

Accordingly, in terms of planning options, we would request consideration is given by Government to such matters as:

- the enhancement of Fringe Benefit Tax thresholds;
- meeting/offsetting the impacts of award/pay equity imposts on providers;
- appropriate promotional and marketing material and campaigns to attract potential staff;
- the development of guidance materials and related support and training resources for health and safety; and
- the structure of levies and incentives regarding safety and workers compensation for the sector.

Technology

As society embraces developments and advances in technology, it is important that the needs, level of awareness and circumstances of people with a disability and those who are ageing are recognised.

At times, disadvantaged groups may experience greater difficulties in using and accessing technology than those faced by the broader community, resulting in lower than anticipated outcomes and an exacerbation of the knowledge gap.

Methods of communication, use of computer based systems and similar technology may further segregate or disenfranchise various parts of the community.

When contemplating planning and service delivery options ifor people with a disability who are ageing, and their carers/families, it is important that due regard is given to the impact of such matters, by way of alternative modes of presenting information, mentoring/support resources, training programmes and the like.

Unmet Need

In addressing planning and service options, it would be remiss not to note the importance of clearly identifying and articulating the present and projected demand for services, from client – family – and service provider perspectives.

It is arguable if official data truly reflects the extent and nature of the demand for future services, given the complexity of circumstances, different Government policy regimes, frameworks and responsibilities and, for want of a better term, the “unknown”.

Given these factors, it is not surprising that there is anxiousness amongst family members, carers and clients regarding support services in the future.

It is imperative that such data be gathered, consolidated and provided in a clear and transparent form to relevant parties, to ensure planning is most effective.

Incentive Initiatives

Government has embarked on a number of incentive programmes over the years, to encourage and reward innovation and effective Government programme implementation.

Given the nature of the disability : aged care interface, it may be appropriate to develop some form of incentives to facilitate innovative programme design and co-operative endeavours between disability and aged care providers, resulting in improved outcomes and a more streamlined, effective system.