Scope

Submission to

Senate community affairs references committee Inquiry into planning options and services for people ageing with a disability

28 May 2010

Authors:

Dr Helen Cheney
Dr Nick Hagiliassis

Contact:

Dr Nick Hagiliassis
Research Coordinator
Scope
177 Glenroy Road
Glenroy VIC 3046
email: nhagiliassis@scopevic.org.au
website: www.scopevic.org.au

Scope's mission is to support people with a disability to achieve their potential in welcoming and inclusive communities

Contents

Executive Summary

Scope is a not-for profit organization providing innovative disability services throughout Melbourne and Victoria to more than 7,000 children and adults with physical and multiple disabilities. Thousands more people intermittently access our information, support and assessment services on a casual basis. Scope supports people with disabilities to achieve their potential in welcoming and inclusive communities. Scope provide services and supports to people with a range of types of disability and a long-standing expertise in supporting people with physical and multiple disabilities.

A number of people with a disability and their carers are likely to experience considerable uncertainty and stress associated with the ageing process. Much of this stress can be linked to accessing and navigating service systems, especially when this takes place within a context of unclear funding arrangements and a shifting policy environment. Some individuals and families don't know what to do about the change occurring and/or about to take place and others find it extraordinarily difficult to obtain the appropriate support and services they need relating to their changed and changing circumstances.

The issues in this submission are presented in three sections. These broadly relate to the following groups:

- People who are ageing and living with disability,
- Family carers who are ageing, and
- Service providers.

The submission canvasses a range of issues relating to the unique and diverse experiences of ageing for people with disability. There is a focus on the need for appropriate services and a more effective service system. The discussion includes the kinds of services needed, access and equity barriers, the need for coordination across sectors in linking up services and developing standards. A number of factors relating to workforce development for paid carers and professional development needs for aged care service providers in relation to disability are discussed. It is argued that a key group of people in "transition to retirement" needs formal recognition so that they are able to move from supported employment into other arrangements more seamlessly. Planning services for this group are critical, as they are for ageing family members who care for someone with disability.

In this submission Scope identifies an urgent need to acknowledge and address the unique and specific ageing issues for people with disabilities and their families. The submission outlines a number of important measures they have taken to address these issues and ensure that the services they provide are adapting to the changing needs of their stakeholders. Scope sees that there is a need for broader leadership and service responses in the disability, aged care, health and community sectors. Moreover, policy makers and planners need to urgently assess the current and future needs of people ageing with disabilities and to develop appropriate programs underpinned by adequate funding.

Scope has made a number of recommendations in relation to issues raised in the submission. In consultation with people with disabilities and their organizations, it is recommended that the Senate committee undertake to:

1. Consider more flexible definitions of 'ageing', accommodating for the earlier onset of ageing for people living with disability.

2. Consider the need for research and development of universal assessment tools that can be used to measure ageing and assist decision-making around ageing for people with disability. In particular, further research and development work be undertaken to identify a tool or a set of tools for differentially assessing ‘ageing’ and ‘disability’ factors in people with complex disabilities.

3. Review existing funding programs (Commonwealth and State) to ensure that there is adequate support for ageing related life transitions. This should be consistent with person centred approaches, the Disability Discrimination Act and ‘Ageing in Place’ policy frameworks. This review should identify funding shortfalls and recommend where additional or modified funding schemes are needed.

4. Ensure clearer requirements regarding government responsibilities. In particular Commonwealth and State government accountabilities for people with disability who at a ‘transitioning to retirement’ stage of life need to be clearer; adoption a more bilateral approach is necessitated.

5. Ensure person centred transition planning is more readily and proactively available to people with a disability wishing to retire. It is important that planning services be made available to families to assist them with succession planning

6. Propose approaches for building the capacity of universal services (e.g., community health, aged care) so as they may be more inclusive of people with disability who are ageing. In particular, links between disability and aged care services should be strengthened, with a focus on the sharing of expertise

7. Ensure that clear information about rights responsibilities and service and support options is available to carers in a range of accessible formats.

8. Propose measures to ensure that there is adequate investment into paid carer salaries and conditions, workforce development in disability, aged care and health sectors, including through services standards.

9. Consider the need for emergency short to medium term housing and care arrangements. Solutions for addressing unmet need, particularly in the area of reliable and quality respite services, are a priority.

10. Identify responsibilities and set targets for planning of services for people with disability who are ageing and their carers of at least the next 5-10 years. Planning should be broad-ranging and include consideration of inclusion, residential, health, employment, recreation and technology needs.

11. Make further recommendations for national standards for people with disability who are ageing with particular attention to the residential, health and community inclusion factors.

12. Strengthen existing case management structures (in both aged care and disability sectors) including to establish appropriate trigger points that mandate timely referral and support from specialist and alternative service providers.

Introduction

About Scope

Scope is a not-for profit organization providing innovative disability services throughout Melbourne and Victoria to more than 7,000 children and adults with physical and multiple disabilities. Thousands more people intermittently access our information, support and assessment services on a casual basis. Scope supports people with disabilities to achieve their potential in welcoming and inclusive communities.

Central to Scope's work is to ensure Victorians "See the person, not the disability". Therefore, Scope focuses on overcoming the personal, structural and attitudinal barriers that prevent people with disability from participating in community life and works to make our community more inclusive, more accessible and more welcoming.

Scope provide services and supports to people with a range of types of disability. Many people Scope support have physical and multiple disabilities, often associated with intellectual disability, communication difficulties and complex health needs.

Scope stakeholders

Scope's primary stakeholders are people with disabilities and their carers. In many cases it is the family who provides the main source of care for partners, children and other family members living with severe and profound disability. Scope stakeholders also include their own employees and volunteers. A number of Scope employees and volunteers are themselves living with a disability, including those employees working within Scope Business Enterprises. Other Scope stakeholders include service providers that provide disability and mainstream services as well as those people outside of the service system (potential clients and/or employees). Many of these stakeholders (especially those accessing employment services, day and lifestyle services, residential and respite care) are aged 55 and over or otherwise experiencing change associated with ageing.

Key issues:

- People with disability experience a characteristic set of physical, psychological and social changes associated with ageing. According to the AIHW, people with an early onset disability age more rapidly and thus have higher support needs at an earlier age than older people generally (AIHW, 2007, p. 108).

- People with disability and their carers experience significant systems-level changes associated with ageing. Whilst change is invariably a source of stress, stress in this instance is compounded by lack of information about available service pathways, difficulties navigating complex service systems and a lack of clarity of service responsibilities and accountabilities.

- People with disability and their carers experience significant barriers accessing supports and services that are responsive to their changed and changing circumstances. In particular, people who are currently in supported employment programs and yet want to retire from the workforce find it difficult to do so.

- Many family based carers are themselves ageing and are finding it progressively harder to care for their adult children. Concurrently, carers experience anxiety regarding long term care arrangements for their son or daughter with a disability.

Scope understands that this inquiry is an opportunity to influence policy (in disability, ageing, health) and to shape programs and services that will improve the quality of life for people living with a disability and their carers. As a major service provider in Victoria, with particular expertise in complex and multiple disabilities, Scope is keen to ensure that their perspective is considered in this reform process.

Context: statistics and trends

This section briefly outlines some key statistics and trends related to ageing and disability that are relevant to this submission.

National

- Australia's population is growing and ageing (ABS, 2003 cited in AIHW, 2007, p. 84).
- It is expected that the median age will increase from 35.9 in 2002 to 42.3 in 2021 and the proportion of the population aged 65 years and over will increase from 13% in 2002 to 27-30% in 2051 (ABS, 2003 cited in AIHW, 2007, p. 84).
- A related trend, evident in developed countries, is an increasingly ageing population of people with lifelong disabilities. As noted by Bigby, "the proportion of the population that has a disability increases significantly with age, with the largest group being those with age-associated disabilities". While people with disabilities still have a lower life expectancy that the general population, their life expectancy has increased significantly (Bigby, 2004, p. 36-67).
- The AIHW estimated that in 2003 ageing primary carers were caring a spouse or partner (57% of cases), or a son or daughter (29% of cases). A high proportion (44%) had been caring for 30 years or more (AIHW, 2007, p. 112-113).
- In 2005, the AIHW estimated that more than 50% of ageing primary carers had a disability themselves (AIHW, 2007, p. 113).
- In 2005, of 30,300 ageing primary carers, nearly 25% needed help with caring (or had received help but needed more) and close to 8% had unmet demand for respite services (AIHW, 2007, p. 113).
- The AIHW estimates that in response to the increased numbers of people with a severe or profound core activity limitation, the numbers of primary carers will increase by 27% across all age groups between 1998 and 2013. The rate of increase is expected to be greatest in the age group of 60 and above (AIHW, 2007, p. 113).

Victoria

- In 2003 there were approximately 529,900 persons living with a disability aged 60 and over in Victoria (ABS, 2004: Table 2).
- The projected population of persons with a profound or severe core activity restriction living in households aged 65 and over in 2010 was 179,700 (62,000 male and 117,700 female) (AIHW, 2007, p. 150).

- The number of users of Commonwealth State Territory Disability Agreement (CSTDA) funded services in Victoria in 2004-2005 was 75,110 (AIHW, 2007, p. 126).

- Close to 20% of all Victorian carers (primary and non primary) are aged 65 and over (ABS, 2004: Table 27)

Scope

- The number of people aged 55 and over participating in Scope employment services is currently 20% (60/300) of the workforce.

- For many of these employees (50%) the only contact that they have with a disability service is through their place of employment.

- Many of these employees (50%) have been employed for more than 20 years with a significant number (20-30%) for between 25-40 years and some (10%) for more than 40 years.

- In May 2010 there were 103 clients in Scope day and lifestyle services who were aged over 55.

Key Issues for people who are ageing and living with a disability, carers and service providers

The issues in this submission are presented in three sections. These broadly relate to the following groups:

- People who are ageing and living with disability,
- Family carers who are ageing, and
- Service providers.

Clearly there are similar and overlapping experiences shared by each of these groups and many of the identified issues are relevant to more than one stakeholder. At the same time, there can be a range of views held across and within these broad groupings.

People who are ageing and living with a disability

Scope supports residents in supported accommodation, attendees in day and lifestyle services, clients of respite services and employees in supported employment. Across their services Scope is in a position to observe the emerging issues and needs related to ageing, access to services and lifestyle changes related to ageing and retirement.

Personal Profile: Wan

Wan is aged 67 years. She is second generation Australian Chinese with 6 brothers and sisters. She maintains contact with her extended family through regular family reunions and is proud of her family history that can be traced back six generations. For most of her life she lived at home and was cared for by her mother. Her father died when she was 19 and her mother died in 2006 at the age of 92 years. Her mum was a sole carer until at aged 80 she was diagnosed with a serious heart condition and at that point, required assistance with caring for Wan.

Wan has worked for much of her life and has been involved in disability service management and workplace advocacy for many years. As a young woman she worked in the family business and for nearly 25 years she has worked in supported employment. Currently she is working as a receptionist, has no retirement plans and would like to continue working until she is 70.

Before her mother died there had been some discussion of Wan moving to a community residence, however, her mother was keen to care for her at home for as long as she felt able to. After her mother, died Wan continued living in the family home. She had regular carers and was satisfied with the arrangements except that they were not available at night (between 10pm and 7am). Wan developed shingles and as her carers were concerned about contracting shingles, they discontinued the service. She would have preferred to stay at home but her brothers felt she was not safe living on her own. Wan did not want to live with family members as she feels they have their own families. She is happy to rely on them for some forms of assistance but not for her daily and routine care requirements.

Wan thought that she was on the disability register but at some point the relevant department removed her name from this list, and put her on the aged care register. As she was aged 64 and still working, she had thought she would be going to a *group home but there were no vacancies at the time. She moved into an aged care facility where she stayed for 18 months. Most of the facilities she considered were unable to provide the level of care she required. The chosen facility was very nice and good quality, but it was expensive ($2,000/month) and there were a number of problems to do with staffing, security and appropriate care.*

There were only two support workers and one registered nurse for the 50 residents on her floor and a high number of temporary agency staff. Some of the agency staff dealt with Wan inappropriately, such as asking her to do tasks she was unable to do. Notably, they did not understand her disability. She was often treated as if she had dementia (as was the case for many of the other residents). Yet Wan was (and remains) cognitively abled. She herself has been trained in disability support and was able to advise them in caring for others when the nurse was unavailable.

At night she would feel insecure because of the behaviour of other residents. She felt vulnerable at night as her room was not locked and there was only one staff member on the floor. While she had a call buzzer, this could never be answered instantly.

Wan was younger than most and was the only person going to work and requiring a packed lunch each day. This was an 'atypical food arrangement'. It led to conflict with the cook and she was once reprimanded for this. She was told that there would be no more food until the dietician had been informed (the dietician attended the facility on a monthly basis). During this episode Wan felt unsupported.

Staff did not always listen to Wan's preferences about her personal care. She felt that her personal privacy was not respected and that she had lost control over her life. There were a number of issues related to her wheelchair. For example, staff wanted to remove the wheelchair from her room. They wanted to disengage the motor (which allowed Wan to use the wheelchair independently) and to push the wheelchair themselves. At one point, her computer was damaged by a staff person. This left her without an important means of social contact and inclusion.

Living in that facility, she observed that everyone was constantly dealing with death. Residents were regularly losing friends. She sensed a loss of compassion for older people. Workers appeared to maintain professional distance from residents and made insensitive comments when someone had passed away.

On a more encouraging note, Wan felt that some staff members were willing to learn about her care needs. Recreation officers were good at providing activities and many residents had strong support from their families.

Wan applied to Scope for a place in a group home and feels fortunate that one became available. She is happier now due to improved levels of care, greater security and sense of belonging. There is up to seven people living in the house. There is also a higher staff to resident ratio, more individualized and one to one care and more security with people around 24 hours a day. Staff members have Certificate 4 training and experience with disability. Many of the staff have been working in the disability sector for a long time (20-25 years) and mentor newer carers. She feels understood and that her health and medical needs are met. There is a mixed aged group (30–68 years) and the residence feels more like a home environment. She can more easily go out with carer support and can visit her family.

Wan feels that her experience in aged care could have been better if the staff had been trained in caring for people with disability and if there was a higher ratio of staff to residents. She would have preferred more flexibility in matters such as food, and a *greater opportunity for decision making overall. She feels that there are advantages in providing more funds to home and community care and keeping people out of aged care facilities where this is not appropriate.*

Many of the issues raised by Wan are relevant to other individuals and families. The following discussion summarises a number of the key issues for people who are ageing and living with a disability, as observed by Scope.

1. , People with an early onset disability ageing more rapidly

While there is no ‘typical’ ageing experience, for some people with disability, the ageing process is seen to occur earlier in life and to occur faster. This has led to calls for a reduction in the standard retirement age for people with a disability. In some disability contexts the ageing population has been defined as 55 years and above and yet this category has also been rejected as it is seen to reinforce stereotypes around premature ageing (Bigby, 2004, p. 41).

Bigby (2004), among others, argues for a more flexible approach. Where in addition to chronological age, ageing criteria could include

> ***“whether in the absence of illness or physical trauma a person displays greater physical disability and lessened physical resources … (or) diminishing levels of functional skills especially in relation to self-care, personal hygiene and activities or daily living” and an additional consideration is whether the person is seen by themselves and others as an older person and as “preferring to shift to different and age-appropriate activities” (Seltzer et al cited in Bigby, 2004, p. 42).***

Ageing occurs on a spectrum and people with disability can start showing signs of ageing in their 30s or 40s. Therefore any data and analysis that relies on year-specific categories may underestimate the numbers of people experiencing the ageing process and the level of services that will be required for this population.

Moreover, social policy based on narrow categories of year specific ageing, for example, assumptions relating to retirement age (60 or 65 years of age) may be problematic in the context of disability. For example, those who experience age related illness are not always able to access expertise provided by aged care services because they don’t meet the formal age requirements. Clearly, restricting services to certain age groups may lead to people with disabilities being excluded from services they need.

It is important that policy makers and service providers consider more flexible definitions of ageing, accommodating for the earlier onset of ageing for people living with disability. Any policy related to the ageing population should be inclusive so as to ensure equality of outcomes for different population groups.

2. Detection of ageing processes in people with a disability

There is poor early detection of ageing in people with disability. One barrier is ‘diagnostic overshadowing’ in which ageing issues are interpreted as a manifestation of ‘disability’. For example, for a person with a disability who experiences deterioration in their physical or cognitive skills, the potential role of ageing is not necessarily a consideration. Additionally, the ageing process can exacerbate certain disabilities and that there are often complex interactions.

Presently, there is a lack of appropriate tools, instruments and protocols for accurately assessing the role of ageing related factors in people with disabilities, particularly in relation to people with more complex disabilities. In the absence of such a resource or a set of resources, it is difficult for professionals, service providers and also carers to understand the needs of the person, as well as to make informed decisions regarding service and support pathways.

It is important that further research and development work be undertaken to identify a tool or a set of tools for differentially assessing ‘ageing’ and ‘disability’ factors in people with complex disabilities. This will allow for more accurate information, earlier detection of age related issues, and more informed responses appropriate to the needs of the individual.

3. Access to inclusive health care

Many of the issues associated with ageing for people with disabilities and the general population are similar. However, some medical conditions (e.g., high blood pressure, cardiac problems, epilepsy, diabetes) occur at a higher prevalence, whilst issues such as weight management, nutrition, calorie intake, fluids are more pertinent. Despite this need, universal health care services are not always configured so as to be inclusive of people with a range of abilities. For example, mainstream health promotion campaigns concerning issues such as mobility are usually not targeted appropriately for many people with disability. Consequently people with a disability and/or their carers may not have adequate health information on how to prevent health problems associated with ageing, such as health issues associated with decreased mobility.

Moreover, the particular forms of disadvantage experienced by people with disability may be compounded by age and make it harder to access care and support when compared with the general population. Research into people with intellectual disabilities shows that:

> ***“the characteristics and lifelong marginalization of older people with intellectual disability mean they differ from the general population in respect of having poorer health, greater reliance on formal services, poorer informal support networks and limited access to private wealth (Webber et al, 2006, p. 1).***

People with disabilities are also more vulnerable to isolation and depression (Deane, 2009). Scope believes that vulnerabilities associated with existing disadvantage are increased when their requirements cannot be met by existing health care service systems.

It is important to consider approaches for removing or attenuating the factors that contribute to the marginalization of older people with disability in relation to access to quality health care. In particular, approaches for building the capacity of universal health services so as they may be more inclusive of people with disability who are ageing appear a priority.

4. Access to appropriate services

People with disabilities who are ageing have expectations related to access to services that are appropriate to their changing needs. The issues are highlighted in the instance of long term accommodation choices. One consideration here is the Australian government's 'Ageing in Place' policy. The policy has been designed to:

> ***"enable, in those facilities which could offer appropriate accommodation and care, residents to remain in the same environment as their care needs increased" (Department of Health and Ageing, 2004).***

The implementation of this policy will require practical steps to ensure equity in relation to people with disability and to support them in their choices about where they live. Whilst a proportion of people with disability will remain in the same environment as their care needs change, others will see changes in their living circumstances. Some will move from independent or family living into supported accommodation. Others may elect to move from family living into independent living arrangements. Aged care facilities are also an option for some people. Access to accommodation supports that are flexible and based on individual needs is critical.

An Australian Institute of Health and Welfare (AIHW) study suggests that

> ***"either disability services will need to provide services to increasingly older clients with changing needs, or transitional arrangements between disability services and suitable aged care (or other) services … will need to be put in place" (AIHW, 2007, p. 108).***

Rather than fixing on this either/or scenario it is likely that both these options will be needed for an effective response to the range of accommodation, and broader service situations experienced by people with disabilities and their carers.

In response to this direction, disability services need expertise in aged care. Conversely, aged care facilities need expertise in disability. Other important considerations for residential facilities relate to building modifications, staffing levels, culture change, service needs and grouping of residents (Bigby, 2009). Additionally, people with disabilities who are ageing may benefit from extended transition periods and opportunities to change their minds as they enter into and actually experience new living arrangements.

It is important to consider approaches to service delivery that are flexible and responsive to the changing needs and preferences of people with disability who are ageing and their carers. An effective response will require a strengthening of links between disability and aged care services, with a focus on the sharing of expertise.

5. Right to Retire

As highlighted above, approximately 1 in 5 of Scope supported employees are aged over 55 and many of these are considering retirement or exiting from paid work. In working with this group of people, Scope has identified a number of emerging issues. For example, Scope has observed that people with disabilities who want to retire are often involved in protracted negotiations to fund new arrangements using individual packages. Typically they find it difficult to get assistance and decision-making is slow and complicated.

Scope have developed their own initiatives to assist employees make the transition from work to other lifestyle options in ways that are person centred. These strategies are based on a preventative approach where employees are assisted to identify their 'after work' life choices and inclusively manage their transition into retirement proactively rather than on a crisis bases.

It has been observed that employees approaching retirement face high levels of anxiety related to their future. Many of these employees have been involved in supported employment for most of their lives and have had limited involvement in the disability sector, community services and social activities outside of their work.

The main form of support needed is a planning, information and advocacy service. Workers with specific expertise in lifestyle, accommodation and service options are needed to work with individuals and their stakeholders (e.g., parents, guardians, networks, significant others) to determine what options are possible and how to enact these within their particular context. Support may also be needed to assist with the ongoing implementation and review of personal plans.

Scope has observed that there is a need for a reasonable time period between a person's decision to retire and actual retirement so that the lead-time to access identified services can be managed. A transition period of twelve months would give a person time to make a decision to retire or exit the workforce and to explore their options. Decisions will be informed by a range of factors (e.g., financial, support needs, transport, funding arrangements) and some people with disability may need to take additional time to consider these and make a decision.

It is worth noting that delayed or inadequate planning for transition and change can lead to negative consequences in that options may become more limited. As some people get older and have increased support needs they are less likely to be accepted into other service options. In addition to loss of self esteem related to fulfilling life choices, they may also lose some financial benefits (e.g. value of leave entitlements) as their productivity declines due to the application of the current productively based wage system. It is helpful that unlike other employment contexts there is no difference in employee entitlements relating to retirement or resignation.

A key barrier for people wanting to retire is the inability to easily move between programs funded by the Commonwealth and those funded by the State. The different cost structures and funding boundaries between Commonwealth and State programs need to be addressed as a matter of urgency. Currently there are significant numbers of people who want to retire but are unable to make this transition.

It is important that person centred transition planning be more readily and proactively available to people with a disability wishing to retire. It is also important that the process of retirement be made easier through a more bilateral approach from Commonwealth and State governments. In particular, there is pressing need for accountabilities and funding responsibilities to be more clearly defined for people who are at a 'transitioning to retirement' stage of life.

Carers

Scope also supports many carers, such as through the provision of respite services .

Personal Profile: Mr and Mrs H

Mr and Mrs H are in their middle 70s. They live with their 44 year old daughter in suburban Melbourne and they have two older children who live in Victoria. They have been actively involved in community services for many years and have formed relationships with other families caring for children with disabilities. Outside of their community involvements they have a limited social life and have not had a holiday together for 25 years. Mr and Mrs H have both experienced age related health issues and Mrs H has chronic back problems that affect her ability to care.

Their daughter has cerebral palsy with associated health issues, namely epilepsy and asthma and she is susceptible to aspiratory pneumonia. Her health has deteriorated as she has got older, although this has improved since she started peg feeding in 2001. She now needs Ventolin every day (rather than intermittent use) and she requires daily chest therapy. She has regular seizures and Mr and Mrs H monitor this, as well as her broader health, using a diary.

Mr and Mrs H have lived in their family home for more than 40 years and have modified it so that there is an ensuite bathroom joining their daughter's bedroom, while a sunroom has been set up as an extra living area. The living arrangements work well. They see that caring for their daughter is their responsibility and they do not expect their other children to take over caring for their daughter when they are no longer able to provide this care. Theiir daughter has been on a departmental waiting list for a residential place for more than 10 years. They have observed a number of problems with the administration of the waiting list, including a lack of clarity of how it is managed and who gets assistance.

They have not been actively pursuing alternative residential care as they have major concerns about whether their daughter's care needs could be adequately met. In most Community Residential Units, there are only two direct support workers on duty during the day and one during the night. They worry about how staff would handle a medical emergency if there were only one person on duty. Of high importance to Mr and Mrs H is knowing that their daughter will be cared for safely and in a manner appropriate to her needs. Accordingly, the importance of quality staff and stable staffing arrangements cannot be underestimated. Over the years they have observed a high turnover of carers. They attribute this to inadequate funding, which results in low rates of pay for carers. They believe that most people in the community do not value the work of paid carers as they don't appreciate the difficulty of the work and the high level of responsibility involved.

They have serious concerns about the introduction of individualised funding. They expect that it will put more work back on to them and increase their responsibilities in relation to employing carers and managing financial arrangements. They worry about being able to find stable and competent carers and the difficulties of getting high quality and continuous care. They are unsure whether the new arrangements would pay for the current day service or how much this would cost. They know of one older parent who is having to deal with the new funding and was not able to cope with the financial responsibilities and is now getting assistance from her granddaughter to administer this. They are ambivalent about receiving more information about the new *funding arrangements. On the one hand they have questions about how it would work in their situation and on the other hand they don't want to have to contend with yet another change in their service arrangements.*

Currently their daughter attends a Scope day service each day and has been for most of her life. She is picked up from home and dropped off at the end of day. They have a high level of confidence in the carers and the organisation's management. They have had home-based support for four years that provides them with a carer each day for two hours in the morning and three hours in the evening during the week and on Sunday evenings. In general they are happy with the type and level of service, although find it difficult to contend with the turnover of carers (6-8 carers during this time). The HACC support was discontinued when their daughter started peg feeding. They occasionally use one particular respite provider as this service has an active night service and their daughter requires care during the night.

Mr and Mrs H have identified a number of changes that would improve their current situation and help ease their worry about the future.

- *More respite and residential services for people with disabilities that include active night and adjunct care arrangements (e.g., on call nurses) for people with high support needs.*
- *Dedicated ageing specific CRUs with additional staffing, for example between 9.30am and 3.00pm when people are not healthy enough to attend day service or would prefer a routine with more time at home.*
- *A significant government investment in the carer workforce to improve the salaries and conditions of carers as well as ensure ongoing professional development and appropriate industry standards.*
- *More timely and relevant information about government services, such as the workings of the DHS waiting list and individualised funding.*

They feel comfortable with the current arrangements and imagine that their daughter will continue living at home for some time. They hope that she can continue attending the day centre as this has been her life for 35 years and where she gets a great deal of pleasure from social relationships and regular community activities. She is with her peers, who are also ageing and have similar interests, and is supported by a knowledgeable, engaged and committed group of staff.

At this time they are would like to maintain the status quo and continue taking each day as it comes.

Scope is aware that many carers are anxious about what will happen to their son or daughter once they are no longer able to care for them. This problem is especially relevant to ageing parents with middle-aged children living at home. These carers are often reluctant to give up caring for their children. They have concerns about the quality of care that will be provided to their children and they may also have formed co-dependant relationships within the family. Moreover, some carers who have been in the system previously have had negative experiences with service providers and this makes them reluctant to use formal service systems again.

The following discussion focuses on the issues for carers, as perceived by Scope. In particular, Scope believes that it is essential for ageing carers to be able to access appropriate services and specialized planning services.

1. Access to services

A proportion of carers have the information and advocacy skills necessary to identify the choices available within the service system and to access these services. In many cases it is carers who actively engage with service systems and who advocate on behalf of people with disability. Highlighting the critical role carers play in advocating for their own needs and those of their children, the Disability Services Commission (2009) reports that parents are the main source of enquiries and complaints (approx 45%) followed by people with disabilities (approx 20%).
Yet there are many carers who are not empowered to access and negotiate the service system. Carers may be unable to access service systems for a number of reasons such as not knowing their rights and responsibilities, not having sufficient information about services and supports, and not having the practical skills to enact those choices. Literacy, cultural and social factors can also present as a barrier.

In 2006 AIHW sought the views of disability organizations regarding unmet needs. It was reported that aged carers do not use respite services because they don't have adequate information about services, they are not satisfied with the standard and quality of respite or accommodation support and services do not meet the needs of the family and are not culturally appropriate (AIHW, 2007, 184). People identified a need for age and culturally appropriate respite services, flexible enough to meet the needs of particular disabilities. Needs relating to carer retirement, support services to assist ageing carers with long term planning and a broader range of respite options and other support services were also recorded (AIHW, 2007, p. 115-116).

It is generally agreed that poor funding of services has led to a crisis across all areas of the service system. Clearly this crisis situation has a negative impact on carers as well as people with disabilities. The AIHW suggest that the

> ***"problems that result from unmet needs tend to snowball and become whole-of-government and whole-of-community problems (AIHW, 2007, p. 115).***

It is important to ensure that clear information about rights responsibilities and service and support options is available to carers in a range of accessible formats. Solutions for addressing unmet need, particularly in the area of respite services, are a priority.

2. Planning

The need for planning services is critical. Inadequate planning means that needs are often responded to reactively (e.g., family crisis) when choices are further restricted. It is clear that planning for family carers needs to occur earlier rather than later and may take some time. Optimally, planning would involve some transition phase. Careful communication with families to clarify expectations and prepare them for changes in living arrangements, service options and in their new interactions with the service sector is critical.

In some cases, it may be decided that residential care is the best option. However, the experience may present unforeseen problems. Transitions from the family home to supported accommodation may be confronting and be associated with adjustment issues for some carers. Difficulties can arise with 'letting go'. Carers may have limited experience and skills for negotiating their needs with service providers. For the person with a disability, they too are likely to need time to adjust to their new environment in terms of new routines, physical spaces and social dynamics, as well as living away from their family, sometimes for the first time.

Parents also face the issue of succession planning for their son or daughter. In this instance, parents may need advice on range of financial, legal and guardianship matters, as well as future residential and care options, from a range of professionals and sources.

It is important that planning services be made available to families to assist them with succession planning. Support (e.g., counseling) also should be made available to assist families in their adjustment to key transitions, where needed.

Service Providers

There is little doubt that the disability sector has made positive change in providing services to people with disabilities. Person and family centred approaches are increasingly driving service delivery, as are principles of choice, inclusiveness and equality. As people with a disability live longer, a new set of challenges presents to service providers. A range of sectors will need to build the capacity of their workforce. There also needs to be effort dedicated to tackling service gaps, achieving key service standards, and improving access to services. Perhaps most critically, there needs to be strengthening of coordination of programs, particularly across those that are the responsibility of Commonwealth and State governments.

1. Professional development

In 2009 Scope had a total of 1,646 employees, with the majority of these being engaged in service delivery roles. A significant number of these staff have worked in their roles for many years. However, the changing needs of our clients has meant that some practices have needed to shift commensurately. For example, 10 years ago only 5% of residents in supported accommodation used gastric feeding tubes and now this is 20%. This has clear implications from a professional development perspective.

Scope is committed to maintaining a skilled and quality workforce. There are numerous examples of where Scope have identified and delivered training in areas relevant to ageing. For example an education program on skin integrity, which is identified as a key health issue associated with ageing, has been initiated. This is just one example of how Scope as a disability agency is building the capacity of it's workforce in the area of ageing. However, not only do disability workers need expertise in some aspects of aged care, but conversely, aged care, allied health and other workers need expertise in disability.

The professional development and training needs for employees in all sectors needs to be identified, assessed and planned. Other factors such as core competencies, roles and responsibilities, implications for remuneration and risk also need to be considered.

It is important to explore mechanisms (e.g., training, practice guides) for building the capacity of the workforce across all (relevant) sectors to more effectively respond to the needs of people with disabilities who are ageing and their carers.

2. Service gaps

Scope is committed to ensuring that the services we provide are appropriate, responsive and inclusive. Yet, there are significant restrictions to flexibly supporting people transitioning out of work or from regular day and lifestyle services. As one example, Scope is supporting an individual who wishes to move from employment to another situation .This individual has been waiting three years for a decision from the relevant department on an individual package. Currently Scope is funding the choices of this person, however, this is not sustainable.

There are no specific funding and programs for individuals and/or groups who are ageing and who need care separate to existing employment and lifestyle programs. Even more rudimentary, there is also a lack of data regarding who is requiring assistance. The available information reflects only those who are already in the system and hence may not be representative of the needs of the broader population. Further work is needed in establishing the extent of this unmet need.

It is important that services for people transitioning out of work, or from day and lifestyle services, be flexible and responsive. Further research is needed to understand the types and degrees of unmet needs.

3. Coordination of Service System

In Victoria a program of individualized packages and person centred planning is leading to major changes in the way services are provided. At times there appears to be a tension where funding cannot be matched to what some people actually want. Moreover, tensions between service sectors are becoming apparent and there is a need to build relationships with other sectors (aged, palliative care, acute and primary care). It is inevitable that some overlap and irregularities will occur and so flexibility in the system and the attitude of services providers is paramount.

Sectors outside of disability are not necessarily attuned to disability issues. This appears the case in aged care where there appears a stronger reliance on the medical model and where different costing models and methods of assessment are used. Disability and aged care sectors need to find better ways of working together so that services available to the general population are accessible and appropriate to people with disabilities. In particular, access will be improved with cooperation between nursing care and disability support workers and clear demarcation of roles and responsibilities between sectors and individuals who are providing care.

Time and resources need to be specifically dedicated to support cooperative service provision. There is a need to agree on thresholds of certain conditions and ‘trigger points’ that ensure that needs for specialized care are identified and addressed in a timely and efficient way. Moreover, it needs to be clear who is funding services.

Moreover, there is lack of clear responsibility between Commonwealth and State governments for people with disability who are transitioning to retirement. The issue relates to that mentioned earlier, namely that people with an early onset disability age earlier and more rapidly. This means that whilst they are functionally ageing much earlier, they do not meet the age criterion for Commonwealth funded programs.

It is important that a coordinated approach, which requires linked up services, cooperation and communication between individuals and groups, is adopted. It is critical that governments clarify their areas of responsibility and work together bilaterally to ensure that people who age early do not fall between the gaps.

4. Planning services for people wanting to retire from the workforce
Scope is a longstanding employer of people with a disability. As employers responsible for managing human resources, we are providing transition planning support to a number of individuals. This is largely through a process of providing information in an accessible format (such as the retirement resource developed by Wodonga TAFE) and general counselling. Referrals to the Scope person centered planners have been made for a proportion of these people.

Scope has identified that specific resources and specialized support are needed to support the transition from supported employment. Expertise is needed for whole of life planning and a clearer policy framework that allows for a transition period, as employees become service users and clients. A 12 month transition period would appear realistic.

There may also be benefit in considering a new category of employee, namely “transition to retirement employee”. This could be either managed through additional flexibility within the ‘stretch capacity’ or a separately funded stream and would remove the financial impost that employees are currently experiencing through having to fund their move into activities whilst in transition. It is important that FaHCSIA agree to such transition periods so that they can be incorporated into contractual arrangements and that modified conditions relating to capped places and remuneration are considered.

It is important that specialized assistance to support the transition from supported employment be more firmly established, and funding models for employees in transition be explored.

Conclusion

Scope has identified an urgent need to acknowledge and address the unique and specific ageing issues for people with disabilities and their families. Moreover, they have initiated a number of important measures to address these issues and ensure that the services they provide are adapting to the changing needs of their stakeholders. Scope sees that there is a need for broader leadership and service responses in the disability, aged care, health and community sectors. Moreover, policy makers and planners need to urgently assess the current and future needs of people ageing with disabilities and to develop appropriate programs and adequate funding.

Recommendations

In consultation with people with disabilities and their organizations, it is recommended that the Senate committee undertake to:

1. Consider more flexible definitions of ‘ageing’, accommodating for the earlier onset of ageing for people living with disability.
2. Consider the need for research and development of universal assessment tools that can be used to measure ageing and assist decision-making around ageing for people with disability. In particular, further research and development work be undertaken to identify a tool or a set of tools for differentially assessing ‘ageing’ and ‘disability’ factors in people with complex disabilities.
3. Review existing funding programs (Commonwealth and State) to ensure that there is adequate support for ageing related life transitions. This should be consistent with person centred approaches, the Disability Discrimination Act and ‘Ageing in Place’ policy frameworks. This review should identify funding shortfalls and recommend where additional or modified funding schemes are needed.
4. Ensure clearer requirements regarding government responsibilities. In particular Commonwealth and State government accountabilities for people with disability who at a ‘transitioning to retirement’ stage of life need to be clearer; adoption a more bilateral approach is necessitated.
5. Ensure person centred transition planning is more readily and proactively available to people with a disability wishing to retire. It is important that planning services be made available to families to assist them with succession planning
6. Propose approaches for building the capacity of universal services (e.g., community health, aged care) so as they may be more inclusive of people with disability who are ageing. In particular, links between disability and aged care services should be strengthened, with a focus on the sharing of expertise
7. Ensure that clear information about rights responsibilities and service and support options is available to carers in a range of accessible formats.
8. Propose measures to ensure that there is adequate investment into paid carer salaries and conditions, workforce development in disability, aged care and health sectors, including through services standards.
9. Consider the need for emergency short to medium term housing and care arrangements. Solutions for addressing unmet need, particularly in the area of reliable and quality respite services, are a priority.
10. Identify responsibilities and set targets for planning of services for people with disability who are ageing and their carers of at least the next 5-10 years. Planning should be broad-ranging and include consideration of inclusion, residential, health, employment, recreation and technology needs.
11. Make further recommendations for national standards for people with disability who are ageing with particular attention to the residential, health and community inclusion factors.

12. Strengthen existing case management structures (in both aged care and disability sectors) to establish appropriate trigger points that mandate timely referral and support from specialist and alternative service providers.

References

ABS (Australian Bureau of Statistics). (2004) *Disability, Ageing and Carers. Commonwealth of Australia*. Cat. No. 4430.0. Canberra: ABS.

ABS. (2003) *Population Projections, Australia 2002 to 2101*. Cat.no. 3222.0. Canberra: Australian Government Publishing Service (AGPS).

AIHW (Australian Institute of Health and Welfare). (2007) *Current and future demand for specialist disability services*. Disability Series Cat. No. DIS 50. Canberra: AIHW.

Bigby, C. (2009) *Ageing with a lifelong disability: issues, evidence and solutions.* Paper presented at 44th Australian Society for the Study of Intellectual Disability conference, Power and Passion: Progress through Partnerships, 4-6 November, 2010. Hobart.

Bigby, C. (2004) *Ageing with a Lifelong Disability: A guide to Practice, Program and Policy Issues for Human Services Professionals.* London: Jessica Kingsley Publishers.

Deane, Kirsten (2009) *Shut Out: The Experience of People with Disabilities and their Families in Australia.* National Disability Strategy Consultation. Prepared by the National People with Disabilities and Carer Council. Canberra: FaCHSIA.

Department of Health and Ageing (2004), *Review of Pricing Arrangements in Residential Aged Care - Full Report*. Ageing in Place Policy (retrieved May 25, 2010 at http://www.health.gov.au/internet/main/publishing.nsf/Content/health-investinginagedcare-report-index.htm~health-investinginagedcare-report-2.htm~health-investinginagedcare-report-2-3.htm

DSC (Disability Services Commissioner) (2009) Annual Report 2008/2009, Melbourne: DSC.

Edwards, B., Higgins, D., Gray, M., Zmijewski, N., & Kingston, M. (2008) *The Nature and Impact of Caring for Family Members with a Disability in Australia.* Melbourne: Australian Institute of Family Studies.

Scope (2009) *Annual Report 2008/2009*. Melbourne: Scope.

Webber, R., Bigby, C., McKenzie-Green, B., & Bowers, B. (2006) *Mapping the Terrain: Ageing people with lifelong intellectual disability living in residential aged care facilities in Victoria*. Quality of Life and Social Justice Flagship. Melbourne: Australian Catholic University and Latrobe University.

Acknowledgements

Scope would like to acknowledge the following people for contributing to this submission:

Anonymous person with disability (Wan)
Anonymous family carers (Mr and Mrs H)
Diana Heggie, Scope CEO
Marie Huska, Scope Health Planner
Jacqui Wilson, Scope Business Enterprises
John Faye, Scope Client Services, General Manager,
Erin Wilson, Scope Adjunct Research Fellow
Phillipa Angley, National Policy Advisor, NDS
Collette O'Neil, Senior Policy Adviser, Victorian Office for Disability