AbilityOptions™

9th June 2010

Committee Secretary
Senate Community Affairs Reference Committee
PO Box 6100
Parliament House
Canberra ACT 2600
By Email: community.affairs.sen@aph.gov.au

Dear Sir/Madam,

Please find attached a submission for the **Inquiry into Planning Options and Services for People Ageing with a Disability** on behalf of Ability Options Limited.

Our organisation is part of the **Futures Alliance** who provided a submission to this inquiry. Our submission details our specific experience as a provider of disability support services.

Ability Options has been providing support services to people with a disability for over 30 years. We current support people through the following programs:

- open employment
- supported employment
- supported living
- case management
- self management support
- post school and day program options
- community development and training.

The organisation currently supports over 2000 people and their families across NSW.

The **aims** of the organisation include:

- To promote the independence, worth and dignity of people with disabilities.
- To provide a range of supported living options for people with disabilities.
- To promote employment opportunities and conduct work and other training for people with disabilities.
- To provide counselling and any other assistance to people with disabilities to encourage and effect their participation in their community.
- To liaise with other community agencies to improve existing services offered to people with disabilities.
- To encourage and promote citizen and self advocacy for people with disabilities.

The **mission** of the organisation is to:

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- To provide people with disabilities better opportunities that will enable them to enhance their lifestyles and achieve their goals.

Our **vision** is to achieve this through:

- Quality services benchmarked through national and international standards of best practice;
- To provide a range of services across Australia that will increase opportunities for independence and choice, strengthen relationships and participation within the community and produce measurable improvements in quality of life;
- Being a dynamic organisation with a focus on continuous improvement; and
- Providing people with a disability opportunity to drive change within the organisation.

Ability Options has been **proactively** seeking to find solutions to best meet the needs of people with a disability as they age. This is a **critical** issue for those the organisation supports. Three issues to be highlighted from our submission are:

1. The capacity to meet increased needs due to ageing is inhibited by ageing/disability delineations. Therefore lack a lack of coordination and program integration at the State/Federal levels.
2. Gold Star housing – that meets universal accessibility guidelines – is required to ensure the capacity for integrated support options across a spectrum of support needs.
3. Allocation of assistance should be based on functional supports needs across all programs.

We look forward to being able to comment on the draft report. The terms of reference for this Inquiry, and outcomes have a strong correlation with the Productivity Commission Inquiry into the long term Care and Support needs of people with a disability, along with the Aged Care Inquiry. From our perspectives there is an interconnection in terms of reference and outcomes sought by our stakeholders.

Please do not to hesitate to contact me if you require any additional information.

Yours sincerely,

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People with Disabilities who are Ageing

Executive Summary

People with disabilities are living longer and greater numbers are experiencing aged related needs. Disability services, like other sectors and service providers in Australia, are facing new challenges relating to the ageing of the Australian population.

Ability Options has engaged in research to identify the issues for people with disability who are ageing, to develop service innovation and responsiveness to meet the aged related needs of people the organisation supports. The organisation established a 'Healthy Ageing Project' in 2007. Our research[1] sought to identify and develop service systems and resources that could facilitate and support the right of people with a lived experience of disability to enjoy their later years, living with good health, dignity and choice within community settings.

The issues identified include:

- Assessment and identification of the needs of people with disabilities who are ageing;
- Staff skills and training in understanding ageing and disability;
- Working collaboratively with aged and community care services and health care professionals;
- The capacity to provide higher levels of support to prevent admission to Aged Care and to maintain capacity to live in the community and home of choice;
- Exploring retirement and semi-retirement options for people with disabilities who are ageing;
- Identifying resources to meet age related needs of people with disabilities who have age related needs at an earlier age (on average) than the broader community.
- Attracting capital funding to build homes to gold star access standards.

Through our research a framework for supporting individuals who have disabilities as they experience age related needs has been identified. Policy delineation based on age is a barrier to meeting the needs of people with disabilities as they age.

Background

People with disabilities are living longer and greater numbers are experiencing aged related changes in their needs. Over the last decade there has been concern within the disability sector, as to how to meet changing support needs as a result of ageing. Many people with disabilities experience ageing earlier than the broader population, in addition to having more complex needs.

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[1] Ability Options, Hayter and Bray consulting and training, 'People with a Disability who are Ageing: An Options Paper', July 2008.

Ability Options estimates that for the next 20 years, at least one in three people accessing our services will experience age related needs and will require appropriate formal and informal community based supports to meet those requirements. A copy of the literature review from our research is included in Attachment A. The people most affected within our services are those with an intellectual disability, with a dual diagnosis, and those living on their own or with their ageing carers without formal supports.

Policies, programs and funding are separated into those for people with disabilities (under 65) and for people who are ageing (over 65). This creates delineations by program and across jurisdictions that inhibit the capacity to respond to the needs of a person across their life. There are also resource restrictions that impact on the choices available, to be able to plan for the future and to support opportunities available to the broader community. The recently announced changes to funding of health services will not resolve the issues of present jurisdictional arrangements.

Policies that facilitate continuity of service provision and reduce program silos are required to ensure the needs of people with disabilities who are ageing are able to be met. Ability Options is active in seeking service delivery responses to meet the changing needs of people with disabilities who are ageing, to prevent premature admission into Aged Care, to have cohesive service delivery options and to maintain quality of life, engagement, choice and control.

The following principles should underpin service delivery and responses to the needs of people with disabilities who are ageing and include:

The individual needs of the person are at the centre of support and care

People with disabilities need to be at the centre of planning for supports, services and how their functional support needs will be met. The expansion of self directed funding options will increase choice and decisions that are centred on each person and tailoring support to meet each person's needs and lifestyle aspirations. The models of support may include a mix of formal, personal (or informal) and mainstream service supports. It is critical that people with disabilities are consulted about what they want, their needs and how these will be met as they age, and to have real choice about support options.

Many of the people that Ability Options support have allocated/fixed funding with limited options to have resources reviewed to flexibly meet complex and changing needs due to ageing. Across the organisation there are limited possibilities to create flexibility and to create transition pathways. The use of better tools to determine support needs and therefore resource requirements are needed.

People with disabilities have the right to age in their community, to have choice and control over where they live and to avoid unnecessary and inappropriate/early admission into Aged Care

Ability Options has a commitment to continuity of supports and to enable people to live in their own homes for as long as possible. The recognition of people with disabilities as a 'special' needs group in terms of Aged Care funding and legislation

would recognise early onset of ageing. This would provide an incentive to service providers to develop appropriate responses to meeting the needs of people with disabilities. Even better would be an integrated system that resourced people with disabilities based on their functional support needs that was not based on age.

People with disabilities who receive supported living (or accommodation services) are currently restricted from access to Commonwealth Aged Care programs (excluding individuals with an acquired brain injury). This applies to individuals who may be receiving as little as 12 hours of formal support per week. State funded disability services often have little capacity to respond to increased needs due to ageing. Ability Options has some scope to respond to changing needs, and to support individuals to move from a low to high support environment. In addition, to creatively and flexibly utilising existing resources to meet identified needs. However, there are limits to flexibility. For example, where additional support resources are not available or there are no program vacancies. Where localised solutions are not able to be found individuals are at risk of entering Aged Care and breaking the continuity of care. This is often to the detriment of the individual who is removed from their support and social networks. There is a lack of appropriate options for people whose who have increasing support needs.

For example:

> *Elizabeth is a 44 year old lady with a bright personality and a love of music and socialising. She was living on her own in the family home with support from HACC services and her social network. She was hospitalised following a fall in June 2009 after fracturing a vertebrae. An ACAT assessment was completed which concluded that she required 24 hour high level care. Elizabeth is now living in a nursing home as this was the only safe option available. The average age in the nursing home is 83 and Elizabeth shares a room with 3 others.*
>
> *Elizabeth is hoping that in the future she will be able to live in her own unit/space with access to support and people her own age to engage with. Elizabeth now has day program funding that she self manages, which she currently uses to engage in community based social and recreation options using a mix of formal and informal supports.*

We are aware of other examples where people under the age of 65 have moved into Aged Care due to resource issues that prevent the capacity of existing services and options to meet changing needs. Aged Care services operate on a lower dollar funding model than disability services and this affects the capacity to meet the needs of people with disabilities. There should be continuity of standards and accountabilities across both the Aged Care and Disability Sectors to ensure human rights are maintained.

Gold Star Building design, integrated support and continuity of supports

Ability Options is actively seeking to provide choices and options to individuals to be able to live in a home/situation of their choosing as they age. One strategy is to build homes that are accessible and will provide an environment where higher levels of

support and care are able to be provided as people age. Universal building standards and designs should be adopted as public policy – or gold star buildings.

Ability Options has developed a housing master plan following our research into the needs of people with disabilities as they age. The organisation is actively investing resources to upgrade housing stock in line with these principles to better meet the needs of people with disabilities as they age. Ultimately our objective is that people with disabilities have access to a home that is affordable, of high quality and accessible. To meet specific ageing related support needs and to ensure capacity to maintain continuity of care our immediate priorities are to build accessible buildings and that enables appropriate equipment to support very high support needs such as ceiling rails, hoists, electric beds, height adjustable chairs etc. Our objective is to ensure continuity of support, to prevent premature admission to Aged Care and to support people to die in their home. Our current capacity to meet the high support needs of people with disabilities as they age is inhibited by lack of appropriate community housing options, along with access to nursing supports.

We are also seeking partnerships to support our endeavors to build affordable and accessible housing to meet the need of people with disabilities and to increase appropriate housing options. There has been a significant investment in community housing over the last 18 months, and this needs to continue. Partnerships between housing providers and disability services, or directly with people with disabilities, are critical to enable the integration of housing and support.

Many people with disabilities are asset poor, and in many instances also cash poor. There is little understanding of the capacity to make a contribution to the development of assets. Options such as shared equity models have the potential to facilitate planning for the future, security and continuity.

The current crisis driven system of disability funding is also a barrier to supporting people with disabilities and their families to effectively plan for the future. There are many families who are proactively seeking options to plan for the future. Often they are only able to do this where they are able to self fund. Our experience with supporting families to manage their supports has demonstrated the value they derive to achieve quality of life objectives. A reduction of program silos and guideline restrictions would assist people with disabilities to meet their needs a holistically and to be proactive in determining their future.

Assessments, needs identification and eligibility that is sensitive to ageing changes

A key strategy to meeting the needs of people with disabilities as they age is to identify changes in support needs. Assessment tools need to be sensitive to ageing changes for people with disabilities. Ability Options uses the ICAN (Instrument for Classification and Assessment of Support Needs) developed by the Centre for Disability studies for all individuals within the supported living. This is completed every two years and feeds into their planning. The ICAN is used to identify functional supports and can track changes that may occur.

We have also introduced the use of the MINDA assessment tool, developed by MINDA disability services in South Australia. This is specifically used for

individuals with identified age related changes and is used to assess and track changes in functional capacity.

These tools are flags to identify changes and to assist in service planning. People with disabilities require access to health professionals, allied health services, general practitioners and gerontologists etc who are able to assess and address age related changes and needs. The Centre for Disability Studies health clinic is an excellent example of a service specialising in disability health. This clinic only has funding to operate for two days per week.

Partnerships and cooperation between the Disability, Aged Care Sectors, Health

Partnership between the Aged and Disability Sectors are required to facilitate collaboration and cross sector development and for staff development and training in disability and ageing. The Innovative Pool Pilot was a great example of partnerships between disability and Aged Care providers. The Disability Aged Care Interface Pilot (DACIP) that was established under the Aged Care Innovative Pool (IP). It was a Federal Government initiative through the Department of Health and Ageing.

The pilot was aimed at people with disabilities with Aged Care needs who live in supported accommodation funded under the then Commonwealth State/Territory Disability Agreement (CSTDA) and who were at risk of entering residential Aged Care. The 'National evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot' Final Report was released in 2006. It is unclear why the program ended in 2007 (grandfathered).

This program provided:

- Early identification of needs related to the ageing process and assistance services required;
- Deliver age-appropriate services based on individuals needs delivered in their existing community setting;
- Developed the skills of disability support staff in age specific needs through collaboration with Aged Care and allied health services;
- Promoted greater understanding of the needs of people with disabilities who are ageing amongst Aged Care providers and ACAT assessment team;
- Increased access to allied health assessment, therapy, support and advice in line with the care plan;
- Provided resources to enable higher levels of personal assistance provided within their existing services and to support active engagement in their community;
- Improved access to aids and equipment for age-related needs;

The average age of people from Ability Options services who accessed this program was 60 years – ranging from 45 to 83 years. All individuals have a primary intellectual disability and other diagnosis including epilepsy, cerebral palsy, bipolar/OCD, depression, deafness, multiple personality disorder, schizophrenia.

Aged related issues that resulted in referral to this program included falls, reducing mobility, incontinence, osteoarthritis, diabetes, dementia, vision loss. 60% of the individuals were referred due to concerns relating to dementia.

The program has:

- Prevented premature admission into Aged Care;
- Maintained independence and skills through the use of equipment and aids;
- Supported active engagement, including capacity to maintain employment;
- Resulted in improvements in health, strength and mobility;
- Supported access to alternative day programs for some individuals who were exited from their disability based day programs.

Disability services have the capacity to meet the needs of people with disabilities, additional training and specific skill set or resources are required to enable continuity of care and meeting support needs.

This would include being able to access community nursing services or the resources to employ nurses for medication and health monitoring.

Retirement options

Along with uncertainties around planning for the future for people with disabilities, there are many uncertainties regarding retirement or semi retirement options. For example:

> *Jenny is in her 50's and has been working 4 days per week. Her work hours have recently been halved over the 4 days, as she is no longer able to manage working for a full day. Jenny lives at home with her mother. The only formal support she receives is through her employment. Jenny's mother is worried about what will happen when she can no longer work.*
>
> *Oscar is also in his 50's and works full time in supported employment. He is no longer able to stand in the afternoon. Oscar lives on his own with support from his family. His family is concerned that if he is not at work that he will sit at home on his own.*

Ability Options is working with each individual and their support network to establish transition to retirement plans that provide ongoing forms of meaningful engagement for people as they age and retire.

A number of people with disabilities who are ageing and/or their families do not have access to superannuation, savings or equity that they are able to drawn on to enable choice in where, how they live and to maintain an active retirement. In the absence of formal supports or resources, a focus is on linking individuals into community based support and activities.

Within accommodation support services there are similar issues where people are no longer able to access day programs or continue working. Service providers are in the position of having to provide the additional support due to an absence of appropriate alternatives.

Ongoing research to provide evidence to inform policy, planning and service provision

Ability Options own research during 2007/2008 resulted in 18 recommendations to guide the development of a framework to support ageing in the community, service responsiveness and meeting the needs of people with disabilities as they age. Through this process and through ongoing participation in research, the organisation has increased our capacity to respond to the needs of this target group. The organisation continues to actively pursue strategies and to remove barriers to meet the needs of people as they age and to provide appropriate community based support options. Ongoing research to inform policy, planning and service provision is required, along with collaboration between all levels of government and the community sector.

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Attachment A - Literature Review Findings[1]

4.1 Demographics

People with disabilities are living longer and experiencing aged related needs. In 1998, 5.5% of the Australian population had a severe or profound core activity restriction and this rate rises significantly with age (AIHW: 2000). Reaching 'an old age' is now a reality for some people with an early onset disability(acquired before the age of 18), with 11% (30,200) of people aged between 45-64 years and 4% (13,000) of those aged 65 years or over, who identified as having an early onset disability, also reporting that they have severe or profound core activity restrictions (AIHW, 2000).

Between 2000 and 2006 the total number of people with a severe or profound core activity restriction is expected to increase by 11.6% (137, 600 people). This suggests that since 2000, there has been an increase of at least 12% in the number of people using disability services who now have a severe or profound core activity restriction. And it is likely the actual growth rate is even higher, as people with a disability are more likely to experience age related issues earlier in their lives, and more people with a disability are living longer (AIHW, 2000). For people who have a disability, age related needs are very likely to be evident when they are in their 50s and 60s, and in 1999, 15.8% of people who use disability services were aged 50 years and over with 6.1% aged 60 years and over (AIHW, 2000).

The challenges of supporting people with a disability as they get older is becoming a reality for most disability services now, but will only increase in the near future. Indeed, the statistics offered by the AIHW and others are seen first hand in the client group of Ability Options. Ability Options estimates that for the next 20 years, at least one in three (30%) clients accessing their services will be experiencing aged related needs, and will require appropriate formal and informal community based supports to meet those needs.

4.2 Ageing and Quality of Life

The process of ageing "is part of a lifelong journey, of individual lives embedded in changing social contexts, hence of complex interplay between biographic and historic time" (Hagestad & Dannefer, 2001:7). Ageing is a process which at an individual level involves many dimensions of change including physical, psychological and social. People with a disabilitiy experience similar aged related needs as the general

[1] Ability Options, Hayter and Bray consulting and training, 'People with a Disability who are Ageing: An Options Paper', July 2008, pp. 18-27.

community, but many also experience some unique and distinctive challenges. A person's quality of life and the adequacy of support networks (both formal and informal) will impact on their experience of ageing (Bigby, 2004: 19).

Maintaining quality of life is a core aspiration for all of us as we age. Considering the quality of life for people with a disability who are ageing is also critical. Schalock and Alonso (2002:27) highlight eight key life domains that contribute to a person's quality of life which include:

- Physical well being;
- Emotional well being;
- Interpersonal relations;
- Material well being (e.g. housing, productive, meaningful activities, income);
- Personal development (e.g. maintenance and development of cognitive and adaptive functioning);
- Self determination;
- Social inclusion; and
- Rights.

The supports provided to people with a disability throughout their life across all of these areas, and particularly as they age, are critical in terms of ensuring quality of life.

Nolan, Davies and Grant (2001) have developed a "senses framework", and they argue that working towards these senses is a critical part of the ageing process particularly for people with a disability. This framework emphasises the importance of informal supports to sustain and support a person with a disability who is ageing. The formal support services should therefore complement and support the informal support networks. The framework identifies seven senses being:

1. A sense of security – attention to physical and psychological needs to feel safe from pain or discomfort and receive competent sensitive care;
2. A sense of continuity – that is recognition of the individual's biography and connection with their past;
3. A sense of belonging – opportunities to maintain or develop meaningful relationships and connection with the community;
4. A sense of purpose – including opportunities to engage in purposeful activity, identify purposeful goals and exercise choice;

5. A sense of achievement – opportunities to meet meaningful goals and make a recognised and valued contribution;
6. A sense of significance – to feel recognised and valued as a person of worth and that you matter as a person; and
7. The individual is at the centre of all relationships.

The United Kingdom of Great Britain Foundation for People with Learning Disabilities on the Growing Older with Learning Disabilities Project has proposed a Charter of Rights for Older People with Intellectual Disabilities. These are the right to:

- Develop person centred plans to meet current and future needs;
- Develop and maintain the person's friendships;
- Maintain links with the person's families when they have left home;
- Lead full lives with activities of the person's choice both during the day and also at evenings and weekends;
- Have choices about where the person lives and with whom;
- Have access to services which can adapt to the person's predictable age-related needs both with respect to staffing and to their environment;
- Have access to independent advocacy; and
- Have physical and mental health needs met.

People with disabilities should:

- Have access to regular health checkups and screening to prompt treatment if they become ill;
- Have their religious, cultural and ethnic needs respected; and
- Be cared for in terminal illness, as far as possible in a familiar environment that supports and respects their wishes (Foundation for People with Learning Disabilities, 2002).

A critical component of supporting people who are ageing is the early identification and management of the health needs. This is discussed in next section.

4.3 Formal and Informal Supports

People who have an intellectual disability experience many of the same aged related biological changes and associated health issues as older people in general. However, due to a range of direct and indirect factors, people who have an intellectural disability generally have a poorer health status than their counterparts who do not have a disability. This difference may be the result of genetics, lifestyle, health condition, disadvantaged socio-economic status and poor health care experiences in earlier life. Pre-existing health conditions of some people with an intellectual disability may also increase their risk of the impact of age-related diseases (Bigby, 2004).

The characteristics and lifelong marginalisation of older people with intellectual disability mean they differ from the general population with respect to having poorer health; greater reliance on formal services; poorer informal support networks; and limited access to private wealth (Haveman, 2004;Janicki et al., 2002; Bigby, 1997). Bigby (2004:73) identified the following health issues experienced by people with intellectual disabilities as they age:

- People with specific syndromes may have a different pattern of ageing or higher risk of particular age-related diseases (e.g. high risk of early onset of Alzheimer's disease found in people with Down Syndrome);
- The high proportion of people with intellectual disability who lead sedentary lives, who may be at risk of aged related diseases such as diabetes, stroke, heart disease, hypertension and respiratory disease;
- The social circumstances of people with intellectual disability and low socio economic status are often not conducive to good health care;
- Even where people are living in accommodation support services research indicates that they are still at considerable risk of poor health and fitness related problems;
- People with Down Syndrome are likely to experience premature ageing occurring from 40 years. They may also have a higher risk of cardiovascular problems, heart disease and thyroid problems;
- People with cerebral palsy during middle age report reduced mobility, increased pain and bladder problems from their 40s;
- People with intellectual disability have a higher risk of psychiatric problems than older people in the general population. This is partly due to the higher incidence of dementia (see also Cooper, 1997);

- Diagnosing Alzheimer's disease can be difficult in people with a disability. Regular monitoring of adaptive skills in required by health professionals to complement other critical medical screening to ensure that changes are monitored. Janicki (1996 et al) suggests that people with Down Syndrome should be monitored from the age of 40 years for symptoms of Alzheimer's disease;
- The effect of abuse and / or trauma on people with a disability in early life can also be a predictor of potential mental health problems as they age;
- Accessing grief and loss support services to understand grief, death and dying. The impact of grief on people with a disability as they age can be significant and this, coupled with communication difficulties, can mean that people may have difficulty expressing their grief.

A range of strategies can be implemented to support people with intellectual disability who are ageing to ensure good health. These include:

- Supporting older people with intellectual disability to live a healthy lifestyle (e.g. through encouraging regular exercise);
- Adequate screening of individual health conditions are essential to early detection and treatment of health conditions and should be done as part of the person centred planning process;
- Engagement of general practitioners and allied and primary health staff on understanding of the issues facing people with intellectual disability who are ageing. This needs to be undertaken in partnership with the person's primary carers to understand the health needs of people with intellectual disability;
- Changing the environment to support people to live in their environment for as long as possible (e.g. lighting in homes, non slip strips, modifications to ramps, supporting the use of communication devices);
- The allocation of additional resources and support staff to support people with a disability who are ageing;
- Develop outreach models to support healthy ageing for people with a disability (e.g. appointment of a community health nurse in an Aged Care Assessment Team to develop skills and expertise for older people with intellectual disability);
- Employment of Clinical Nurse Specialists with specialist skills in disability and ageing to work with staff and people with a disability in planning their care;
- Development of specialist geriatric assessment services for people with intellectual disability who are ageing;

- Development of health related educational materials for people with intellectual disability; and
- Developing programs to understand grief and loss and the strong emotions associated in supporting a person who is experiencing grief and loss (Bigby, 2000:82-85)

The role of health care professionals and the importance of having a lead agency or case manager to monitor the health care needs of people with a disability are also important. In a review of reportable deaths of people with a disability living in care, it was found that in most cases, there were significant barriers for people with a disability in accessing appropriate primary health and specialist medical care. Issues were also raised in terms of supporting people with a disability with end of life decision making and working with health care and other professionals to understand the needs of people with a disability in terms of end of life decisions (NSW Ombudsman, 2006).

Understanding death and dying is another important area for consideration in supporting a person with a disability as they begin to age and reach the end of their lives. Harper and Wadsworth (1999) suggest the following strategies be implemented:

- Education and preparation for death;
- Honesty and involvement in the rituals surrounding death;
- Listening, observation and support of people to express their emotions;
- Education of families and professionals (including through the development of information and resources);
- Resolution and negotiation of different approaches with professionals with families;
- Identification of need for and acquisition of specialist help if needed;
- Avoiding significant changes in a person's life, or skills assessment for at least 12 months after the bereavement; and
- Providing bereavement care and counselling services.

4.4 Recreation and Work Opportunities

Retirement and changing the work/life balance affects all people as they get older. Research indicates that a high proportion of older people with a disability value continued active engagement with their world. They express the desire to continue working, continue learning and participate in leisure activities. Despite their aspirations,

older people who have intellectual disabilities experience fewer opportunities to participate in meaningful day and leisure activities of their choice. For people with an intellectual disability who are older, access to support determines whether they can access social and recreational activities. The most commonly sought after outcomes of day programs for older people with intellectual disabilities are:

- Exercising of choice;
- Strengthening of social networks;
- Participation in the community;
- Skill maintenance; and
- Opportunities for the development of self expression or creativity (Bigby, 2004).

In a national survey of programs serving older people with intellectual disability undertaken by Krauss (1990) there were three basic program options for providing activities:

- Age integration – which means including older people in programs for younger people with a disability;
- Generic integration – including older people with a disability in programs for the general aged population, for example, attendance at senior citizen's centre, day centres for the frail aged, community leisure and recreation programs.
- Specialist programs – developing specialised programs for older people with a disability for example, day centres dedicated to older people with intellectual disabilities.

Day placements for people with a disability who are ageing need to shift to be seen as lifestyle support. Day programs that are built around lifestyle support can provide opportunities for activities that are not centre based but based in the community or at home. There needs to be a connection between maintenance of skills, health and social networks for individuals as part of lifestyle support. Bigby (2004:149) proposes some key criteria for lifestyle support which include:

- Provision of choice and individualised planning;
- Maintenance and strengthening of social networks;
- Support for participation in the community;
- Maintenance of skills through a range of strategies including education;
- Opportunities for self expression and sense of self; and
- Promotion of health and a healthy lifestyle.

4.5 Accommodation and Support

Supporting people to age in their community is a philosophy supported by state and federal governments in Australia. This is expressed in policy as service standards that promote and insist on maximising choice for older people and provision of services that enable them to remain in their community of choice for as long as possible. This philosophy is referred to as "ageing in place". The NSW Ombudsman has stated that the concept of ageing in place for people with a disability is an area that requires further policy development (NSW Ombudsman, 2006).

Many people with a disability who currently live in supported accommodation are now entering older age. Bigby (2004) identified a number of key issues relating to supporting people with a disability to age in place including:

- The capacity of shared support accommodation services to adapt the environment type and level of support as an individual's needs change;
- Providing affordable, accessible housing and security of tenure for older people;
- Identifying when relocation to a specialist aged care service might be considered;
- Review of decision making processes around relocation decisions; and
- Support available for the process of relocation.

Bigby's (2000) research showed that people with intellectual disability are very susceptible to unstable housing conditions as they age. In the study of 62 people with intellectual disability, by the age of 65 years and over, two thirds who had lived with their parents were living in an aged care facility. In addition Bigby concluded that "supporting people with intellectual disabilities is not an intuitive skill, it will be the adoption of effective working methods backed by good judgement and staff training which will result in the delivery of support" (Bigby 2000:167).

A recent study of people with intellectual disability living in residential aged care facilities in Victoria identified a number of service difficulties relating to supporting these persons within this environment (Webber, Bigby, Mckenzie Green & Bowers, 2006). This study achieved a good sample, with just over one third of Victorian residential aged care facilities participating. The study found that the largest proportion of residents were living with family prior to their move into residential aged care, and were generally admitted when their carer became ill or died; when their own health deteriorated; or when family members could no longer provide the level of care and support the person required (Webber, Bigby, Mckenzie Green & Bowers, 2006).

The study also found that most people with intellectual disability were significantly younger than other older people living in the residential aged care settings. The key care and issues identified in the study were:

- The need for appropriate and individualised activities;
- Difficulties with providing for younger residents in an environment where their needs are often different from those of older residents;
- A high level of' 'one to one' interaction required for many residents with intellectual disability;
- Difficulties with managing inappropriate behaviour, especially when staff time and resources are limited or stretched when attempting to gain access to support services;
- The need for staff training and sometimes having insufficient staff resources (Webber, Bigby, Mckenzie Green & Bowers, 2006).

Fine and Thompson (1995) highlight some of the challenges of enabling ageing in place for people with a disability, arguing that it can be difficult to identify who could be supported to live in a community setting and who may need support in a more highly supervised and structured environment. It is often the nature and availability of informal support, rather than an individual's characteristics, that determine whether a person is able to live with independence within the community setting.

The evidence suggests that shared supported accommodation is as effective for older people with a disability as for younger people with a disability. However, Bigby (2004) has identified some of the key areas of difficulty in supporting people with a disability to age in place including:

- Accommodation funding models based on full time attendance at a day program for residents;
- Lack of resources or flexibility to respond to changed support and care requirements for people with a disability;
- Concerns about the safety and well being of frail persons in mixed age houses;
- Poor design and adaptability of houses;
- Lack of expertise and skilled assessment capacity;
- Inability to access external specialist resources to support the person to meet their individual needs (particularly health needs); and
- Misconceptions about ageing.

Bigby (2000) found examples of blended packages of care between aged care and disability services that have supported people with a disability who are ageing. The situations that fail do so are generally due to the following:

- Lack of thorough assessment of support need;
- Poor communication between support workers and poor monitoring; and
- Inadequate balance between choice and risk and the use of directive support.

Blended care models are worthy of consideration with respect to supporting people with a disability who are ageing. One example of a blended care model is the Key Ring Model. This model aims to build a network of mutual and informal community supports for a small cluster of people with a disability, living within walking distance of each other, in either shared or single accommodation. A community worker lives in each network providing backup or on call support or advice and supports people to be active within their community Bigby (2004).

To compliment these kinds of models, Bigby (2004) identifies a range of strategies to manage need including:

- Design and building modification – the impact of the built environment and supporting people to age in their environment with appropriate modifications;
- Staff training and education– including the employment of a specialist in the aged care field (e.g. a Registered Nurse or specialist person in aged care who can act as a resource for other staff);
- Changes to staff mix and resourcing (on call staff rather than constant staffing, staffing that is linked to peak periods of service);
- Use of external services to provide specialist assistance (e.g. people with a disability who need to be able to access domiciliary nursing services);
- Providing a mix of accommodation options to meet the diversity of resident needs in terms of ageing, the more options available by the service means more choice for people; and
- Designation of specific houses for older people (purpose built houses for people with a disability who are ageing).

4.6 Palliative Care and End of Life Decision Making

As people age, issues arising from end of life decision making are inevitable. There can be a number of issues for disability services in terms of supporting the end of life

decision making and palliative care for people with a disability who are aged. Concerns have been raised about the process of involving people with a disability and their carer, family and/or advocates in this process as well as having clearly documented procedures to respect the rights of people with a disability while maintaining the duty of care of the service supporting the person with a disability (NSW Ombudsman, 2006).

The NSW Department of Ageing, Disability and Home Care (DADHC) recently released a Palliative Care Policy providing guidelines for DADHC operated and funded accommodation support services with respect to end of life decisions and palliative care (DADHC, 2005). The policy defines palliative care as "the total active care of people whose disease is not responsive to curative treatment" (DADHC, 2005:3). Palliative care is delivered by coordinated medical, nursing and allied health services and is provided, where possible, in the environment of the person's choice. It is important for Ability Options to develop systems that support the person with a disability who is ageing with end of life decision making, as well as managing their duty of care, and the DADHC policy would be well suited.