

Futures Alliance –

Seeking Better Futures for People with a Disability who are Ageing

16th August 2010

Inquiry into Disability Care and Support
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

Dear Sir/Madam,

Please find attached a submission into the **Inquiry into A Disability Care and Support Scheme** on behalf of the Futures Alliance.

The Futures Alliance is a cooperative of community representatives with a single focus on removing boundaries and maximising community resources to deliver improved options for people with a disability who are ageing.

We also seek to:

1. To promote and raise awareness of the existence, needs and experiences of people with a disability who are ageing – **we want be able to tell people's stories to the decision makers.**
2. To promote qualitative and quantitative research and study on the current lifestyle and living conditions for people with a disability who are ageing – **we want to be able to promote debate and disseminate information about the good things and not so good things that are happening in people's lives.**
3. To help identify the concerns of ageing people with a disability and their families and to highlight their suggestions for key practical measures which they would like to see taken – **we want to consult in a genuine and informed way. Consultation means giving accurate and timely feedback.**
4. To research and provide information on current and best practices of support to ageing people with a disability – **we want to have a clear picture of the best options currently available and to share this knowledge.**
5. To determine the style(s) and model(s) of support that can achieve a person centred approach to people with a disability who are ageing – **we want to understand what might work best for people.**
6. To identify existing mechanisms, including funding mechanisms, which enable good practice and any obstacles/barriers to achieving positive outcomes- **we want to let the decision makers know of the possibilities, the urgency and the importance of action.**
7. To initiate strategies for delivering improved services and to advocate for pilot programs/service and support changes to be introduced –**We want to follow through and achieve concrete changes for people.**

8. The Futures Alliance is all about effective **partnerships**, effective **solutions** and effective **outcomes** to deliver self directed and person centred support for ageing people with a disability.

Our activities and objectives are in line with the UN Convention on the Rights of Persons with Disabilities. Representation includes people with a disability, parent, aged care providers, disability care providers and academics (a full list is included below).

The Futures Alliance supports in principle the adoption of a lifetime, no fault entitlement scheme to fund supports and services for people with a disability. The Futures Alliance has produced a Blue Print on Ageing with a Disability and we submit this document for the consideration of your inquiry.

We look forward to hearing from you and are prepared attend hearings to discuss our submission if invited to do so.

Yours sincerely,



Jo-Anne Hewitt
Chairperson

Futures Alliance Representatives:

1. John and Cheryl Morgan, Consumer Advocates
2. Rachael Haggett, Parent Advocate
3. Aine Healy, NSW Council for Intellectual Disability
4. Christine Regan, NSW Council of Social Services
5. Ruth Wilson, Aged and Community Service Association of NSW & ACT Services
6. Jo-Anne Hewitt, Uniting Care Disability
7. Mike Blaszczyk, McCall Gardens Community
8. Nicola Hayhoe, Ability Options Limited
9. Mark Clayton, Sunnyfield
10. Chris Campbell, The Spastic Centre
11. Ed McNamara, United Care Ageing NSW/ACT
12. Mike Furner, Baptist Community Services
13. Paul Sadler, Presbyterian Aged Care NSW & ACT
14. Leanne Dowse, School of Social Sciences and International Studies, UNSW
15. Shannon McDermott, Social Policy Research Centre, UNSW
16. Patricia O'Brien, Centre for Disability Studies, University of Sydney
17. Roger Stancliffe, University of Sydney
18. Catherine Hogan, Family Advocacy
19. Freda Hilson, NSW Guardianship Tribunal
20. Trevor Parmenter, Emeritus Professor

Blue Print on Ageing with a Disability

Executive Summary

For the first time in human history, people with a lifelong disability are reaching retirement age in significant numbers. Factors such as increased access to quality health care, better living conditions and enhanced social supports and participation, have led to improved life expectancy for people with a disability. The Futures Alliance was formed in recognition that current policy and practice in both the disability and ageing arenas fall short of the required response to support people with a lifelong disability as they age.

The Futures Alliance is a cooperative of community representatives from disability and aged care providers in NSW which includes representation from consumers, academics and peak bodies. The purpose of the Futures Alliance is to remove boundaries and to maximise community resources to deliver improved options for people with a disability who are ageing. The Futures Alliance has been formed and has grown via a network of professional relationships with a shared vision of influencing policy pertaining to people with a disability who are ageing and ultimately improving outcomes for this group of people.

We remain hopeful that the recent changes announced under the COAG's National Health and Hospitals Network Agreement will make clearer the funding responsibilities of Federal and State Governments in relation to this cohort. However, without a seamless and flexible approach to service delivery the potential for cost avoidance and cost shifting remains, furthering the likelihood that people with a disability who are ageing will continue to fall through the policy cracks.

Based on current research, consultation with people with a disability, their families and service providers, and an examination of current policy and funding mechanisms we have constructed a "Blue Print" for Ageing with a lifelong disability. The key outcomes identified in this "Blue Print" are as follows:

For People with a disability who are ageing:

- Genuine consultation about what they want and how their aged care needs will be met.
- Self directed individual funding options with the flexibility to meet complex and changing needs.

- Recognition as a 'Special Needs' group within the Aged Care funding and legislative framework.
- Eligibility and access based on assessments that are sensitive to ageing changes for people with a disability.
- Access to all Commonwealth Aged Care Programs, including packaged and flexible care options.
- Access to health, and allied geriatric expertise.
- Ongoing research to provide a solid evidence base for policy, planning and service provision.
- Flexibility and collaboration between all levels of government and their departments.
- Funded partnerships between disability and aged care providers to allow collaboration and cross sector development.
- Professional development of a workforce that addresses ageing and disability issues in practice.
- Consistency between disability and aged care standards to ensure human rights and accountability.

For Governments:

- Improvements to planning and service delivery which minimises the likelihood of people with a disability who are ageing falling into crisis.
- One Government agency charged with the responsibility to co-ordinate planning and service delivery.
- Reductions in unnecessary use of expensive health interventions, such as hospitalisation
- A more equitable system, where people's needs are met irrespective of how they arise.

For Service providers:

- Better exchange of knowledge across aged care and disability services.
- More effective use of resources through better targeted assessment.
- Capacity to support people to continue to live in the community as they age.

For Communities and Families:

- Reassurance that people with a disability who are ageing will have their needs met.

- More effective support for carers.

Issues

The Australian population is ageing and so too are people with a lifelong disability. The number of people with intellectual and psychiatric disability increased markedly between 1993-1998 and the number of people who have severe or profound disability who are over 65 has increased from 337,600 in 1993 to 1,238,600 in 2003 (Australian Institute of Health and Welfare, 2000, 2008). People with early onset disability, such as intellectual disability, also experience the ageing process at an earlier age than the general population (Australian Institute of Health and Welfare, 2000).

Like all of us, the key issues for people with a disability as they age include questions such as: Where will I Live? How will I maintain my quality of life? What will I do with my time when I retire? and; Who will support me if I am sick or need help? People with a disability often experience the ageing process earlier, and their needs are frequently more complex than the general population.

For a person with a disability there is a greater risk of unnecessary and inappropriate institutionalisation throughout their life course and this risk increases as the person, and their carers and support network, age. Many people with a disability have experienced social isolation throughout their lives and at the point where their requirements for support are increasing their informal support network is often dwindling or breaking down.

People with a disability require support to have choice and control over where they live, and adequate resources and supports to remain active into retirement. Many people with a disability have had disjointed work histories and therefore access to funds via superannuation are often limited or absent. In addition, people with a disability often get the support they need such as personal care or social supports in the workplace or via a day program. Retirement is often not an option as these essential supports are often not available throughout the day at home.

People with a disability who are ageing deserve the same choices that reflect the range of options available to other people as they age. This can only be achieved via access to a service system that allows them to plan for the future and to participate in the implementation of these plans.

Current funding and policy frameworks preclude this and people with a disability who are ageing are frequently falling through the cracks of a disjointed service system. Contract guidelines and program boundaries do not facilitate the coordination of services from both the disability and aged care sectors to support

people with a disability who are ageing. In contrast, people with a disability who are ageing require a service system, ready and enabled to respond to their needs. This will be achieved via access to complementary funding and services from the disability and the ageing sectors and from coordinated State and Federal funding programs.

Stakeholders

Many people with a lifelong disability have not expected they would grow old. For those with significant physical disabilities this is the first generation that has considered the possibility of outliving their parents. In addition, for people with cognitive and psychiatric disabilities, the concept and implications of growing old may not be something they have considered or even understand.

Family members and carers may not have planned for the ageing of their family member because of a lack of expectation that they would age, compounded by a lack of services available to consider and plan for. Many families are faced with the increased challenges of caring for a person whose needs may be increasingly complex due to early onset ageing at the same time as they are experiencing the ageing process themselves.

Disability services are impacted by the ageing of their clientele in a number of ways. As people with a disability age their needs increase and become more complex. Disability services often lack the flexibility in their funding regimes to cater for these increased needs. For example, a person who may have previously been well supported in a block funded group home may be unable to receive the level of care and expertise required once their physical or cognitive functioning is effected by dementia, or to meet increasing physical support needs. This effect is also particularly pertinent for people living in the community, who may receive intermittent or drop-in support from a disability provider and are currently unable to access complementary services from an Aged Care provider due to “double dipping”. In these situations people with a disability who are ageing are at increased risk of being forced to exit a service or their home and move into residential aged care due to a lack of other options.

Disability services require policies to enable the needs of people to be met as they age and to ensure the cross pollination of disability and aged care expertise. Where the focus of the disability sector has been on supporting social inclusion, there is an increasing imperative to up skill the workforce to meet more complex health and medical needs of people with a disability as they age.

Equally, there are many challenges for the Ageing sector. Assessment of the ageing needs of a person with a lifelong disability is complex and often difficult. This can act

as a barrier to people with a disability being considered eligible to access an Ageing specific service. Many mainstream services for ageing people are reliant upon informal supports to back up service provision eg: the direct support of a spouse or child of the older person. For many people with a disability who are ageing, their primary supports have been their parents, who are themselves ageing or no longer alive. In addition, there is a converse skills gap where workers in ageing services are often focussed on health outcomes and are unable to meet the essential social and communication needs of people with a disability. There is an imperative to ensure that the workforce in both the ageing and disability services are skilled to respond to the myriad needs of people with a disability who are ageing and that people have access to complementary and coordinated supports.

The ageing of people with a lifelong disability impacts not just the individuals with a disability and their families but the whole community. The current lack of a comprehensively planned system increases the likelihood that people with a disability who are ageing will fall into crisis. The risk of expensive health interventions such as hospitalisation increases, without an equitable system where the needs of people are met irrespective of how they arise.

Solutions

To find solutions there must first be genuine consultation with people with a disability who are ageing, their families and carers and advocates, about what they want and how their aged care needs can be best met. The Futures Alliance supports the provision of Self-Directed individual funding options that give people and service providers the flexibility to meet complex and changing needs. Such funding arrangements are in place in some Australian states however others such as NSW are still providing block funding to disability services and self-directed options are only available to select clients within a small number of pilot programs.

The Futures Alliance calls for people with a disability to be granted recognition as a “Special Needs” group within the Aged Care funding and legislative frameworks. This recognition is currently afforded to, for example, people from Aboriginal and Torres Strait Islander communities, who also face access barriers, and for whom the aged care planning age is set at 50 years and over (compared with 70 years and over for the general population) because of a shorter life expectancy and the earlier onset of chronic disease. Similarly, recognition in the “Special Needs” category for people with a disability who are ageing would facilitate a targeted planning approach as well as promote priority of access where required and ensure that responses to their particular needs are developed within Aged Care services.

Accordingly the Futures Alliance calls for access to all Commonwealth Aged Care Programs, including packaged and flexible care options for people with a disability

who are ageing, regardless of where they are living. Access to these supports should enhance and not replace the disability specific funding or services that people have required throughout their lives. Currently people with a disability who live in supported accommodation funded by state governments are not eligible for in home support for their ageing needs by programs such as HACC. This can result in people with a disability in these settings being admitted to hospital or placed prematurely in residential aged care.

People with a disability who are ageing require access to the health, and allied geriatric expertise that is afforded to the rest of the community. This requires development of expertise in this sector including tailored assessments and interventions which meet the complex needs of people with a disability.

Flexibility and collaboration between all levels of governments and their departments would enable opportunities for funded partnerships between disability and aged care providers. Such partnerships foster collaboration and cross sector development and work toward a workforce in each sector that is equipped to address ageing and disability issues in practice.

The Futures Alliance recognises the urgent need for ongoing research to provide a solid evidence base for planning, policy development and service provision.

In addition, the Futures Alliance calls for consistency between Disability and Aged Care Standards to ensure accountability and the promotion of Human Rights.

Results

This “Blue Print” for ageing with a disability has been formulated with input from service providers in ageing and disability sectors, peak bodies, academics and most crucially, people with a disability who are ageing and their families.

In calling for the identified solutions we seek to ensure a better planned system which: minimises the likelihood of people with a disability who are ageing falling into crisis; reduces unnecessary use of expensive health interventions and hospitalisations; promotes the exchange of knowledge across aged care and disability services sectors; uses resources more effectively through better targeted assessment and; delivers a more equitable system to meet peoples’ needs irrespective of how they arise.

We will know that this has been successful when families and communities are confident that people with a disability who are ageing have their needs met; when families and carers are more effectively supported and; when people with a disability who are ageing can say:

- I have chosen the supports I need

- I was able to do this easily
- I can live where I want to live
- I have my own plan for the future
- I am an active valued citizen

Futures Alliance – Blue Print for People with Disability who are Ageing

What

Support to have choice and control over where they live as they age

The option of self directed individualised funding for life

Recognition of the increased complexity of support needs of people with disabilities as they age

Support to have choice and control over where they live as they age

Avoiding unnecessary and inappropriate institutionalisation

Have the same choices that reflect the range of options available to other people in their retirement

Enablement of the disability and aged care sectors to respond to their needs

Clear and uniform access to supports to meet needs

Recognition that people with disabilities often experience the ageing process at an earlier age than the general population

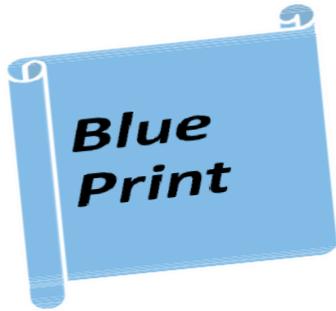
Why

Are now living longer and reaching retirement age

Their needs are not being met
People with disability are falling through the cracks

Lack of cohesion between funding and policy frameworks results in disjointed service provision

People with disabilities would like access to a system that allows them to plan their future and to participate in the implementation of these plans



Who

Government:
Federal
State
Local

People with a Disability

Aged Care Services

Disability Services

Human Services

Community:
Social Networks
Advocates
Family
Volunteers

How

Genuine consultation about what they want and how their aged care needs will be met

Self directed individual funding options with the flexibility to meet complex and changing needs

Recognition as a 'Special Needs' group within the Aged Care funding and legislative framework

Eligibility and access based on assessments that are sensitive to ageing changes for people with disability

Access to all Commonwealth Aged Care Programs, including packaged and flexible care options

Flexibility and collaboration between all levels of government and their departments

Access to health, and allied geriatric expertise

Ongoing research to provide a solid evidence base for policy, planning and service provision

Funded partnerships between disability and aged care providers to allow collaboration and cross sector development

Consistency between disability and aged care standards to ensure human rights and accountability

Professional development of a workforce that addresses ageing and disability

Results

People with a disability who are ageing are saying life is good because:
I have chosen the supports I need
I was able to do this easily
I can live where I want to live
I have my own plan for the future
I am a valued active citizen

For Governments:
Improvements to planning and service delivery which minimises the likelihood of people with a disability who are ageing falling into crisis

Reductions in unnecessary use of expensive health interventions, such as hospitalisation

A more equitable system, where people's needs are met irrespective of how they arise

For Service providers:
Better exchange of knowledge across aged care and disability services

More effective use of resources through better targeted assessment

Capacity to support people to continue to live in the community as they age

For Community and families:
Reassurance that people with a disability who are ageing will have their needs met

More effective support for carers

Futures Alliance is a cooperative of community representatives from disability and aged care providers in NSW which includes representation from consumers, academics and peak bodies.

Our aim is to seek better futures for people with disability who are ageing.

For more information see www.futuresalliance.blogspot.com or email: futuresalliance@gmail.com