

**Futures Alliance –
*Seeking Better Futures for People with a Disability who are Ageing***

The Senate Standing Committee on Community Affairs
Legislation Committee
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Inquiry into Aged Care (Living Longer Living Better) Bill 2013

The Futures Alliance is an alliance 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. The Futures Alliance made submissions to the Productivity Commission Inquiry into Disability Care and Support in August 2010, and again in May 2011, in respect to the specific issues facing, and current policy gaps pertaining to people with a disability who are ageing. Earlier this year we submitted a response to the Draft National Disability Insurance Scheme Bill 2012, in this we addressed areas of direct impact of this scheme on the specific needs and issues for people with a disability who are ageing.

Please find attached The Futures Alliance response to amendments to the Aged Care (Living Longer Living Better) Bill 2013.

Yours Sincerely,

Jo-Anne Hewitt
CHAIRPERSON

22nd April 2013

Futures Alliance – Membership

Aine Healy	NSW Council for Intellectual Disability
Brendon Moore	Alzheimer's Australia (NSW)
Cheryl Morgan	Consumer Advocate
Chris Campbell	The Junction Works
Christine Regan	NCOSS
Ed McNamara	Consultant
Robyn Helm	Baptist Community Services
Jo-Anne Hewitt	UnitingCare Disability
John Morgan	Consumer Advocate
Karen Kakolyris	Catholic Care
Leanne Dowse	University of NSW
Louise McCormack	Cerebral Palsy Alliance
Mark Clayton	Sunnyfield
Mike Blaszczyk	McCall Gardens
Nicola Hayhoe	Ability Options Limited
Pat Sparrow	Council on the Ageing
Patricia O'Brien	Centre for Disability Studies
Paul Sadler	Presbyterian Aged Care
Pauline Armour	UnitingCare Ageing
Rachel Haggett	Parent Advocate
Rashmi Kumar	NCOSS
Roger Stancliffe	University of Sydney
Ruth Wilson	Aged and Community Services Association (NSW)
Shannon McDermott	Social Policy and Research Centre
Trevor Parmenter	Emeritus Professor University of Sydney

The Australian population is ageing and so too are people with a lifelong disability. The number of people of all ages with intellectual and psychiatric disability continues to increase. More specifically the number of people who have severe or profound disability aged over 65 years has increased from 337,600 in 1993 to 590,300 in 2009 (Australian Bureau of Statistics, 2009).

The Futures Alliance calls for the Senate Standing Committee on Community Affairs to consider the following points in relation to the Aged Care (Living Longer Living Better) Bill 2013.

1. Given the unique and specific needs of people with a disability who are ageing, the Futures Alliance calls for their inclusion as a distinct diverse community group as classified within the aged care legislative and funding frameworks. We seek an additional amendment to paragraphs 11-3 (b) to (e), to include *'people with a long-standing or pre-existing disability'*.

Recognition as a diverse community under this legislation would encourage service responsiveness and innovation. This would ensure that people with a disability who are ageing are enabled access to increased supports if and when needed.

2. We would argue the needs of this group are such that the Department of Health and Ageing should give consideration to the development of a National Ageing and Aged Care Strategy for People with Disability.

The recent National Strategy documents developed for people from a Culturally and Linguistically Diverse background and the Lesbian, Gay, Bisexual, Transgender and Intersex community, underscore the importance of such documents in recognising the unique needs of special needs populations in our community.

Age – Disability Interface

While aged care has no age requirement, this is not true for the National Disability Insurance Scheme (NDIS). There will be a substantial number of people with life-long/long-term disability who will be over 65 when the NDIS comes into effect in NSW, and as such will have to rely on the aged care system to meet their needs. It is important that the aged care system recognises people with disability as having special needs and that a strategy for people with disability who are ageing be developed to reflect the specific needs of people who require aged care services.

Lizzie has been with Kirinari for 15 years and lives with her friends Jack, John and Wendy in a house very much like yours and mine. If we look back two years we find Lizzie is getting tired and would really prefer not to have to get out of bed at 7.00am so she is ready for the day program bus that will arrive at 8.15am. Lizzie doesn't really want to go bird-watching or bowling, or to be told when to have a cup of tea or when she should eat lunch or to be told that she needs to go to the toilet. Lizzie is after all 62 years old.

Lizzie can't choose when to go to day activity and Lizzie can't choose to stay home and spend a day

relaxing. Lizzie can't do these things because her home is not funded during the day so there is no staff to support her at home. Lizzie is unable to access any aged care support because she lives in supported accommodation, her funding doesn't allow it. Lizzie is unable to enter retirement; Lizzie is unable to age in place.

Lizzie's health declines, the doctors say she has dementia, staff at the day program centre she attends start to say that they can't handle Lizzie. Disability day program staff are not trained to support the ageing person nor are they trained in Dementia support; but Lizzie can't stay at her home because there is no funding to pay staff to be with her. With no policy in place that would enable Kirinari to plan for Lizzie's retirement, where does Lizzie go?

Another twelve months goes by and Lizzie is still getting up at 7.00am to be ready for the bus even though Lizzie is much slower now and requires significant support from her supported accommodation support worker. She still keeps going, or are we making her go?

More time passes and Lizzie starts to take a liking to Wendy's clothes and Bill's bed and forgets what the toilet is for and now hates to bathe. Kirinari struggle to provide Lizzie with a good life, Bill, Wendy and John are suffering but are also sad for their friend Lizzie. The support workers, not trained in aged care, are burning out and feel the support they are giving Lizzie is not enough, they do not know what to do anymore.

Finally there is no choice; day programs refuse to have Lizzie as they are not trained to support an ageing person who has an age related condition. Lizzie's doctor refers her to an Aged Care Assessment Team. It is decided Lizzie requires high level care and Lizzie leaves her home. Today Lizzie is waiting for a nursing home bed at a local hospital, no timeframe has been given. Bill, John and Wendy continue to visit Lizzie, Lizzie continues to recognise her friends.

We would argue the arbitrary age of 65 years should not become a boundary that people with a disability need to cross before accessing appropriate aged care supports and expertise. A greater range of support and service options available to people with a disability who are ageing would avoid the inappropriate placement of people under the age of 65 in residential aged care due to lack of alternative options, or lack of expertise in the community context.

To require someone, such as Lizzie, to move from a system of supports which may have been in place for their entire lives, to an aged care system which may not deliver the same quality or quantity of services, and which would undoubtedly operate within a different framework and philosophy, is an unreasonable and inequitable choice to force upon an individual at this point in their lives.

Ageing in place

The key concerns for people with disability as they age are the same as those for the general population, for example:

- Where will I live?
- How will I maintain my quality of life?
- What will I do with my time when I retire?
- Who will support me if I am sick or need help?

The following case study is a firsthand account of one couple's experience of ageing with disability. John and Cheryl's story illustrates how they grapple with the above questions on a daily basis, and the combined impact of disability and ageing on their lives.

If we didn't plan and adapt to living at home, we would undoubtedly end up in full care in an institution or a nursing home, well before we want to. Each year as our physical abilities deteriorate we assess how this impacts our independence. This story outlines how we manage and prioritise the use of what minimal support we receive from Home Care.

Cheryl, my wife and I both have Cerebral Palsy, we have raised twins, who are now adults and no longer living near us. We are in our late 60's, and we are trying to age gracefully in our own home. To be independent is not about physically doing everything for ourselves; it's about the decisions we make to use support to maintain our physical independence. We want to use our support in way that lasts longer. Living independently is about doing the things that are necessary to meet our physical needs but also to enjoy and participate in life; the same as everyone else in the community.

If we were to do our domestic work, it would take one or two whole days and we would be physically exhausted. To do this we would burn out physically and lose all our independence, Home Care can have it done in two hours. The same with cooking, we have four or five meals cooked by Home Care in one scheduled service and freeze these for the rest of the week, this is a better use of support than having Home Care here to cook five nights per week.

Six days a week I get half an hour personal care, on the seventh day I struggle to do my own cares. This is by choice. I want to be physically able to care for myself in case of personal care emergency or if we go away. It's still a struggle to get out the door, but without that half hour, which is not much, I wouldn't be ready for work or any other activity.

As we age we are struggling more. Our pain and physical needs are increasing. I need help in and out of bed. Cheryl helps as much as she can, but she is also physically limited. It is getting harder for her as she gets older. In fact everything is getting harder and takes longer to do. We work as a team to help one another. It is harder on Cheryl as I need more assistance from her. In this case Home Care is not the answer as the help I need at home can be unpredictable and I also need some help when we go out. Shopping has become a burden. We find there are times we need assistance which is outside our scheduled Home Care service. Our need for unplanned or emergency support is increasing.

Hospitalisation and post-surgery care is becoming the breaking point as the system doesn't allow for increases in service as a result of post-operative care or health issues. Cheryl is required to be at the hospital all day every day to assist me with communication, meals and to get comfortable. Post-operative care is difficult without extra support at home. It is a similar situation when Cheryl has surgery. We have both had much surgery over the last 15 years. At these times we are in jeopardy of requiring permanent fulltime care as we can't sustain ourselves in our own home.

Although we are lucky to own our own home, that comes at a price. Small jobs, which others can do, we can't; it's hard to get tradesmen to come just do to small jobs (e.g. change a light globe or tap washers). Because we own our own home, there are no funds available for home modifications and necessary renovations such as installing ramps or bathroom modifications, as I now use a motorised wheelchair and need a commode. In public housing this is all done for free. Being pensioners on a very low income, we find it difficult to pay for any renovations to support our changing needs.

In summary, we make the best of the little paid support we get to maximise our independence and rely heavily on each other's support. Living with minimal support is becoming more of a struggle as the years go by. Some types of extra support, such as out-of-hours or unplanned/unscheduled support are not available. Modifications and small maintenance jobs are an issue and they have a

very big impact on our quality of life.

Our goal is to live our life as independently as we can. We would like our support to increase and be available when we need it. If we could rely on our support system then it would provide us with greater confidence to continue to live within our own home and not rely on full-time care in a nursing home or disability accommodation facility.

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.

Changing needs

The health needs of people with disability who are ageing are frequently more complex than the general population, and their subsequent use of professional health services is higher (Australian Institute of Health and Welfare, 2012). The established networks of support for people with disability, such as carers and other informal supports are often also ageing, increasing the individual's risk of social isolation and unnecessary and inappropriate institutionalisation.

Susan is 70 years old and lives in group home with four other people. Her home has 24 hour support. Susan has a moderate intellectual disability, bipolar depression, psychosis, obsessive compulsive disorder, osteoarthritis, diet controlled diabetes and hemiplegia as a result of a stroke.

Susan receives support (six hours) through the Innovative Pool Project. The dollar value of support available through this source is static and as such the amount of support she can access decreases as costs increase. To date, however, this funding has enabled additional follow-up in relation to her medical needs, and supported her to participate in activities to maintain/improve mobility and strength, and social community activities and interests. Annual assessments have identified opportunities to help Susan maximise her independence, including the purchase of a lifting chair, modifications to the home, appropriate footwear, related equipment such as a lifting chair, a walking frame, the use of a monkey bar, a lighter wheel chair to maximise self-propulsion and the use of specific food utensils to maximise independence. Maintenance, repair and replacement for this equipment is not available under this funding program.

As a consequence of her stroke, Susan uses a walking frame to help her move around when at home and a wheelchair for when she is outside of her home. She requires full time assistance to help her stand and move around. Susan enjoys social outings to visit family and friends, to go bowling and attend church so it is important her mobility outside of the home is supported, without this support Susan is at risk of becoming socially isolated.

Her mobility issues also impact on Susan's ability to attend to her own hygiene and toileting needs. She has compulsive behaviours around her personal care and toileting that disrupt others if her demands to go to the toilet are not met.

As can be seen by her diagnoses, Susan experiences a number of what might be described as ageing-related health issues. The supports from the funding she receives currently help Susan to continue to live in her current home, despite her increasing dependence on staff in relation to her mobility and hygiene needs. There is concern that in the future, Susan's capacity to remain in her home, with people she knows could be at risk if additional resources to support her mobility and manage some of her behaviours are not addressed.

Disability services are impacted by the ageing of their clientele in a number of ways. They often lack the flexibility in their funding regimes to cater for the changing needs of their clientele. For example, someone like Susan may be unable to receive the level of care and expertise she requires as her physical support needs increase. This 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”. These situations place people with a disability who are ageing 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.

Finally, the Futures Alliance thanks the Senate Standing Committee on Community Affairs for the opportunity to comment on the Aged Care (Living Longer Living Better) Bill 2013. These reforms, together with the advent of the National Disability Insurance Scheme, promise a future where people with a disability can live good lives with choice and control over the services they need and want to use. It is imperative that the critical reforms in both the Ageing and the Disability contexts occur in concert, to ensure that people who are ageing with a disability stop falling through the cracks. We would welcome the opportunity to appear at a public hearing.

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