

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 THE NATIONAL DISABILITY INSURANCE SCHEME BILL

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. 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.

The Futures Alliance welcomes the opportunity to respond to the Draft National Disability Insurance Scheme Bill 2012. Our comments pertain to areas in the legislation that directly impact on the specific needs and issues for people with a disability who are ageing.

Please find attached The Futures Alliance response to the draft legislation.

Yours Sincerely,

Jo-Anne Hewitt
CHAIRPERSON

25th January 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 Futures Alliance welcomes the advent of the National Disability Insurance Scheme pointing to a future where people with a disability will have access to the supports they need to live as valuable citizens in the Australian community. Presently, people with a disability who are ageing experience substantial disadvantage due to current policy and practice. The Futures Alliance is concerned to ensure that the National Disability Insurance Scheme closes the gap of disadvantage for this vulnerable and growing population.

The key to successful implementation of a truly person centred scheme will be in building the capacity of people with disability and their families to understand and articulate what they need, as well as what they want, in order to live a good life.

For a younger, well educated population, these concepts will be something they have longed and even fought for. Those who have been educated in a mainstream school system, those who have a strong support network around them, and those who already have an understanding of their rights, as well as aspirations for a better future, will be well equipped to take up the new funding/service offers.

There are however a number of vulnerable populations particularly representative among people with a disability for whom the new policy and service delivery paradigm may prove difficult. In particular, people who have experienced limited inclusion or choice and control throughout their lives, and including those who are not connected to a family, service or other support network that can promote the persons needs and aspirations. This can include people with dual diagnoses, people living in boarding house accommodation, people with disability in the criminal justice system and those who are homeless or otherwise unconnected from adequate supports. The Futures Alliance is specifically concerned with the impact of the National Disability Insurance Scheme on people with a disability who are ageing.

Many people with a lifelong disability have not expected they would grow old. For those with significant physical and developmental 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. People in this cohort have traditionally relied on services being provided to them in a rationed and group based approach. Whilst the National Disability Insurance Scheme has the potential to enhance this groups' access to the

supports they need as they age there is also the risk that this scheme will further expose the vulnerability of this group whose support networks are ageing or absent.

The Futures Alliance calls for the Senate Standing Committee on Community Affairs to consider the following points in relation to the National Disability Insurance Scheme Bill 2012:

Becoming a Participant

Age Requirements (section 22)

The Futures Alliance would encourage an ongoing evaluation of the scheme in relation to the age requirements. With the ageing population and an extension of people's working lives to beyond the age of 65 in many instances, we believe that the scheme would be more equitable, create greater equality, and be more in line with Australia's human rights obligations if the age requirements were removed or extended significantly so as to broaden the concept of disability and enable those who are ageing with a disability (rather than experiencing age-related diminishment of capacity) to receive the sufficient support for a full life. This would apply to both those people who have a disability before the age of 65, and to those who acquire a non-aged related disability after the age of 65.

Disability Requirements (section 24-25)

There are around 50,000 people with disability in NSW using community care services. Many of these people rely on low level services such as domestic assistance, personal care, delivered meals or community transport to stay in their own homes and in their local communities. This may include someone who only needs personal care or community transport. A large proportion of this cohort is people with a disability who are ageing.

While the NDIS eligibility criteria appears broad enough to admit low level users of community care services, the Futures Alliance are concerned that many of these people may be screened out in a rationalised system.

Experience from the (now disaggregated) Home and Community Care Program shows that people who do not receive timely and consistent low level supports can quickly escalate to very high levels of need. This can lead to the need for intrusive, costly and premature service interventions that could have been avoided with inexpensive and occasional low level supports.

When a person ceases to be a participant (section 29)

The Futures Alliance is concerned that the Bill does not allow for adequate interface between the Disability and Ageing sector ie: an individual to receive both an NDIS package and community/residential aged care packages.

As the NDIS is designed to provide people with disabilities with the adequate support to enable them to have the same rights, certainty and opportunities that the rest of Australian society enjoys, this should also include access to aged care services as required. Ageing, while sharing some similarities with disabilities, is a different process and thus should be treated as a separate range of supports to work alongside the NDIS as a person with a disability ages. This should be the case for both residential and community based care. The Futures Alliance is able to share examples where cross sector collaborations and flexible use of funding packages leads to excellent outcomes for people with a disability who are ageing.

In addition, to require someone 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 a participant at this point in their lives.

Participants Plans

CEO must facilitate preparation of a participants plan (section 33)

The Futures Alliance strongly supports the Bill's indication that plans can be described specifically or generally, whether by reference to a specified purpose or otherwise. We believe this general approach is ideal and should be supported in the implementation in allowing the flexibility and creativity in addressing participant need which would ensure positive outcomes for participants. While there will be in some cases the need for specific supports to be provided to participants, we would encourage a general approach which is focused more on the goals, objectives and aspirations of the participant, in the context of their living arrangements.

In section 33(6) however, it states that, when funding is managed by the Agency, supports will only be able to be provided by "registered providers of supports". This creates a potential disadvantage in both choice and price for those having their funding managed by the Agency. The Futures Alliance are concerned that this requirement may be of particular relevance to people with a disability who are ageing who may have limited informal supports and or/advocates to assist them.

We appreciate that the Regulatory Impact Statement provides the option for low-risk services to be obtained from informal, non-registered services. We would

therefore encourage a higher degree of equity by ensuring that all participants can access low-risk informal services from non-registered providers, regardless of how their funds are managed.

Reasonable and necessary supports (section 34)

The Futures Alliance recommends that the wording in 34(e) is general in nature and could serve to disadvantage people whose family and community supports are limited. Rather the point should include explicit reference to individual circumstance including:

- what the participant wants from family, carers, networks, community
- what the family, carers, networks, community are willing to provide
- what the family, carers, networks, community are able to provide

Reviewing and changing participants plans

Review of participants plans (section 48)

The Future Alliance recognises the capacity within the Bill for the participant to request a change to their plan. It is recommended that a more explicit statement regarding the capacity for immediate review in the event of a crisis be included eg: the sudden loss of a parent or significant means of informal support.

Summary

The Futures Alliance welcomes the opportunity to provide feedback to the Senate Standing Committee on Community Affairs regarding the draft National Disability Insurance Scheme Bill 2012. The advent of the National Disability Insurance Scheme promises to enable people with disability to step outside the traditional service system and live the life they want and deserve. The right policy decisions now will support the realisation of people's dreams tomorrow.