

**Youngcare**

**Submission in response to the National Disability Insurance Bill 2012**

**25 January 2013**

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At Youngcare, we believe all young people deserve a young life.

Further, from lived experience, we know that aged care is no place for a young person.

For these two simple reasons, we wholeheartedly support the proposal for a National Disability Insurance Scheme (NDIS) and the potential it creates to realise our dream of an end to young people living in aged care.

Overall, Youngcare echoes the sentiment of thousands of Australians who believe the driving policy objectives of the proposed scheme as expressed in the NDIS Bill 2012 are sound. However, Youngcare has identified ample opportunity to alter the Bill to ensure that it truly meets the needs of all Australians in an age appropriate fashion.

The needs of young Australians requiring 24/7 care needs arising from severe and profound disability are clearly dramatically different to the needs of the average residential aged care resident. To borrow from the words of an experienced aged care nurse *young people in nursing home beds are just different. They've still got the fight in them.*

At Youngcare, we believe the NDIS, and its key objectives as articulated in this Bill, needs to support these young Australians to keep up the fight for a young life; to never give in to life dominated by the strictures and routines of aged care. To do so, the Bill needs to go further in articulating how it will vary the necessary and reasonable supports available to young Australians with disabilities so as to respond to their irrefutably reasonable claim on a young life.

Our specific comments are provided below:

### **Objects of the Bill**

The different types of support required by people of different ages should be recognised right from the start in the Objects of the Bill. Clause 3 (1) (b) should be amended to commit the Bill to supporting the participation of people with disabilities in *age appropriate* ways. This amendment could potentially go a long way to recognising that the inappropriateness of young people living in aged care is not due to the inadequacy of such facilities in meeting medical needs or basic needs for food and shelter. The inappropriateness stems directly from the fact that it is unacceptable for

young people to be permanently co-located with residents of average age of 83 years and an average life expectancy of three years.

Clause (3) (1) c) should be similarly amended to insert the term *age appropriate* to describe the type of supports a participant will be provided with recognising that what is reasonable at one age is frequently inadequate at another age. This is particularly the case of young people and their social inclusion and participation in the routines and traditions of a young life in Australia.

Finally, in reference to the Bill's Objects, the Bill should not fail to recognise that for Australian's who come to disability suddenly in adulthood, support will be needed not only to achieve goals, but at a more fundamental level to meet any pre-existing and non-negotiable obligations the individual may have already taken on prior to disability; such as parenting and marriage. The Bill needs to take steps to end the current situation where young people forced into aged care, are in cases forced to separate from their children, thus denying those children their right to the emotional support arising from close proximity to one's parent while growing up. Clause (3) (1) (d) should be amended to include the words *and obligations* following goals i.e. goals and obligations.

### **General principles guiding the actions under this Bill**

The key concepts outlined above – the insertion of notions recognising the need for an age appropriateness test of reasonableness and the need to support people to meet their pre-disability obligations – should be filtered throughout the general principles, such as in clauses (1), (3), (4) and (6).

In addition to these amendments, clause (5) should be amended to introduce the concept of *rehabilitation* in addition to early intervention. Youngcare is of the firm belief that the Bill should accept within its definition of early intervention, not only the common usage understanding of an intervention early in childhood, but the more accurate concept of interventions early in the post-injury stage or early diagnosis stage. Such an amendment would recognise the tremendous potential to both mitigate the impact of disability on people's lives as well as the possibility for better recovery (in the case of injury) and the prevention of obvious exacerbations (in the case of degenerative disease such as Multiple Sclerosis) with better support in the early days.

Amendments could also be made to achieve this end to clause 21 (b) to insert a fourth sub clause *prevent further exacerbations of aspects of degenerative diseases which result in disability*, as well as in many other instances such as (27) (1) (b).

### **Participants and their plans**

#### **Assessment**

Youngcare is relieved to see recognition of the episodic nature of some diseases such as relapsing remitting Multiple Sclerosis will be recognised in assessments, and the need for support to prevent predictable exacerbations of the disease in coming years.

As mentioned throughout Youngcare understands that the goals and aspirations of a younger person are significantly different to an older person and that they will require additional support to achieve these goals and aspirations.

Finally the Bill must understand that the young people who acquire their disability suddenly when already a parent, cannot escape their ongoing obligation to parent their child as fully as possible, particularly emotionally. Assessment under the scheme must accept that this person will need additional support to continue to fully discharge this obligation and that failure to provide this support would result in significant negative impact on that child.

## Planning

Throughout plan development the goal planning approach must accept the need for an age appropriate test in settling on approved supports and recognise that goals change dramatically through life, and that the goals of a young person are dramatically different to that of an older person. Additional support will be needed to achieve those goals, particularly those around social inclusion and participation.

In considering plan management provisions, the Bill must recognise that young lives rarely run according to tight schedules. Fast changing plans, quick decision making and even a bit of plain old fashioned disorganisation are common features of a classic young Australian adulthood fondly remembered by many. Whilst it is not the responsibility of the Australian taxpayer to foot the bill for bad planning by an individual, Youngcare insists that there be some flexibility for some supports to be varied within a budget without Agency approval. For example it will be critical for young people to be able to bank some hours of funded support to attend a once-only special event such as a music concert by a major act who may only be in Australia for a short period or major sporting event such as grand finals etc which occur only once a year and often can't be made to fit the usual schedule of support.

## Interface with aged care

Confidence in continuity of care as one ages is a real and constant worry in the lives of people living in Youngcare Apartments. Youngcare supports the suggestion of the National Disability Service (NDS) that *Legislation should allow access to the NDIS for people who have a diagnosis of a listed degenerative condition (such as motor neuron disease, multiple sclerosis or post-polio syndrome), even if at age 65 they do not yet need formal support services.* Youngcare is also satisfied with the NDS's suggestion of a time limit of age 70 years be introduced for the appearance of symptoms. Whatever happens, the transition between young care and aged care must be smooth and not characterised by inane bureaucratic discriminations.

Further, Youngcare also insists that all people under 65 living in residential aged care have access to NDIS-funded supports. Further, if they remain in residential aged care after that age, Youngcare insists that they continue to receive the additional services they have previously been assessed as reasonably requiring, taking account of their changing life goals as they age. In particular, Youngcare insists that they retain NDIS funded assistive technology and equipment.

## General Comments

Youngcare agrees with the massive majority of NDIS respondents who have repeatedly and emphatically demanded that the NDIS must be not just an injection of more money into a thoroughly broken, fragmented, unfair, inefficient and useless system. The NDIS must be a radical

overhaul of the entire approach to assisting in the care of some of Australia's most vulnerable and disadvantaged citizens.

Youngcare supports the provision of some block funding into the future in cases where market failure is predictable and should be planned for. Supported accommodation for young people with 24/7 care needs is the classic example of this situation where, due to a dire shortage of places 7,500 young Australians have today ended up forced to live in aged care. This is clearly inappropriate and must be solved via the implementation of the NDIS. However, it will not be solved overnight simply because of the logistical incapacity of the specialist housing industry to fund, plan, deliver and transfer a sufficient amount of appropriate housing stock in the short time left available until the full implementation of the NDIS.

Remaining on the topic of infrastructure provision, despite the introduction of this Bill there remains an urgent need for further information on the Scheme and Agency's plan for the funding of necessary hard infrastructure such as supported accommodation for the 7,500 young people currently living in aged care due to the insidious interplay of a dire shortage of alternative places with the lack of appropriately funded ongoing care packages.

Youngcare seeks further urgent clarification if the intention in further developing the scheme is to adopt the approach put forward by the Productivity Commission in 2011 report:

*The NDIS would not own the 'bricks and mortar', but the funding it would provide would cover the cost of capital. The Commission considers that there are strong grounds for individuals to have capacity to cash out specialist disability housing ... this would involve estimating the value of rent (priced at the market rate) for a given person using support accommodation, which could then be cashed out for accommodation services."*

In closing, Youngcare is delighted to have had the opportunity to comment on such milestone legislation. The NDIS presents significant opportunity to redress the shocking situation of young people living in aged care and it is an opportunity we must all foster every step of the way.

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