

Australian Productivity Commission. Response to request for NDIS feedback especially

“How the NDIS impacts on, and interacts with, mainstream services and ensuring the best possible outcomes for people with profound or severe permanent disability”

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July 6, 2017 Position Paper - NDIS & Senior Australians – A Multiple Sclerosis Perspective

Multiple Sclerosis Network of Care Australia

Getting it Right is a Challenge – What has happened to Lifetime Continuous Care?

Since the NDIS was first introduced there have also been ongoing, significant changes in the nature and scope of support available to senior Australians living with Multiple Sclerosis – resulting in far too many mixed messages – including from NDIS field staff, MyAged Care and Service Providers.

Based upon ongoing feedback, including extensive first hand experiences, the MS Network of Care provides the following overview of what has been happening and asks the question “What has happened to the long standing commitment for access to Lifetime Continuous Care delivered by a multi-disciplinary team for those diagnosed with Multiple Sclerosis?”

The following position paper highlights many of these issues whereby the Productivity Commission might ensure a far more inclusive message to all diagnosed with MS regarding the supports to which they are entitled - irrespective of age.

About the Multiple Sclerosis Network of Care Australia <http://www.msnetwork.org/index.htm>

What is Multiple Sclerosis?

Australia has an MS population of at least 24,000. It is one of the most common progressive neurologically associated diseases among young adults and is more common in women than in men. It is frequently diagnosed between the ages of 20 and 40. 74% of all cases are women. Less than 5% of patients present with MS before the age of 16. Its impact, which can be mild, moderate or severe, is associated with more than 20 of the most common aspects of daily living and escalates exponentially over time. At the 20 year mark population studies show that 35% of people living with MS are significantly to severely impaired. Lifetime Continuous Care programs delivered by multi-disciplinary teams are identified as essential for those with more advanced forms of MS.

<http://www.msnetwork.org/roadmap/whatisms.htm>

Consumer Directed Care

The principles of consumer directed care (including NDIS) whereby funding is provided directly to those most in need of care (as opposed to bulk funded agencies) are well suited to the MS environment. What is inconsistent with this environment is the diversity of entry points to continuing support programs and the ways in which such programs are restricted according to variables such as age, means testing and capped dollar support - without effective regard to what MS families have worked tirelessly to put in place, at times over many years. In a recent survey by the MS Network of Care frustrations flowing these complexities were summed up as follows:

“I am 66 and already receive home care support. While my needs have increased and more support is urgently needed I am too scared to ask for additional help because of what it may now cost me.’

More about lifetime continuous care <http://www.msnetwork.org/bookmarks/lifetime-care.htm>

About the MS Network of Care’s Position Paper on the aforementioned topics

Following are extracts from this paper as at 6 July 2017. The paper incorporates extensive links to associated evidence. Feedback is welcome.

<http://www.msnetwork.org/expectations/ndis-gaps.htm>

NDIS and Beyond -

The National Disability Insurance Scheme (NDIS) is a social insurance scheme designed to transform the way disability services are provided in Australia. Traditionally, disability support funding was provided to service and care providers in block payments. The premise of the NDIS is to provide this funding directly to people with a disability who qualify for the scheme and to assist them to make informed decisions about the best supports and services they require to help live their life to the fullest.

Why is there an age 65 Threshold?

This is a result of a recommendation by the Productivity Commission enquiry that underpinned the introduction of NDIS. It said “DisabilityCare Australia is not intended to replace the aged care system, and the age 65 threshold ensures that there is not duplication between DisabilityCare Australia and aged care”.

The need for Lifetime Continuous Care is under-recognised

Such an assumption is, however based upon a mistaken belief that the disability related needs of all of those 65 and above are adequately covered by age related subsidies provided by the Australian Department of Health. However it is long established that in the case of many severe chronic disabilities, including multiple sclerosis, the needs of many are best addressed through multidisciplinary lifetime continuous care programs (see earlier) tailored to specific individual needs.

More about lifetime continuous care <http://www.msnetwork.org/bookmarks/lifetime-care.htm>

Role of Supplementary Care Plans

Rarely are service providers in receipt of Australian government subsidies (especially in rural/regional Australia) able to fully offer such comprehensive and at times highly specialised support. In such circumstances complementary individual Care Plans, built around localised support, are often established by those in need under the guidance of their GP (often part of a GP care plan) in consultation with their primary carers/advocates.

Something is Seriously Wrong

Supplementary funding for the Plan (where needed) is sourced as appropriate - including through specialised agencies in receipt of related bulk funding. Unfortunately the premature (especially in NSW) government unilateral withdrawal of all bulk funding - without providing immediate and viable alternatives has caused the collapse of many of these vital Care Plans - something is seriously wrong

Responding to Criticisms

In responding to such criticisms in April 2012 the Minister said that "the 'Living Longer, Living Better' program, referred to as Consumer Directed Care (CDC), coming into effect from 1 July 2012, will deliver more choice, easier access and better care for older Australians and their families with measures such as" : *Additional support and care to help older people remain living at home; *Additional help for carers to access respite and other support; *Establishing a gateway to services to assist older Australians in finding information and to better navigate the aged care system - subsequently known as My Aged Care; *Self-directed funding

Existing NDIS Members can now elect to retain NDIS Benefits when turning 65

In March 2013 the Australian Government further responded to criticisms by amending the law whereby people who turn 65 and are existing NDIS participants can choose to remain as NDIS participants or transfer to the existing range of aged care related services provided by the Australian Government.

This was a sensible decision as disability needs vary significantly from one individual to the next. Importantly it leaves the decision in the hands of those needing care. Unfortunately, left unresolved are the rights of the transition group, i.e people who would otherwise qualify for NDIS but who are, or may be, over 64 when the scheme formally commences in the area in which they live.

Discrimination based on Year of Birth

The practical effect of this is that all Australians born after 1950-1955, (depending upon when/where the scheme starts) with qualifying disabilities will have options to choose based upon individual circumstances. Those born earlier will not. By any measure this is wrong but can be easily fixed though political will.

It is highly discriminatory to create two classes of people over 65 based solely on their year of birth. This is a matter about which we all need to be very much aware. While it is estimated that around 40% of Australia's current MS population are in the negatively affected age category. A lesser

number have disability support needs that are not being properly addressed – solely because they are being denied a choice available to others in the same age grouping.

Revised Home Care Packages

A Home Care Package is a coordinated package of services tailored to meet the consumer's specific care needs. From 1 August 2013, a new Home Care Packages Program, based upon the principles of Consumer Directed Care (CDC), replaced the former programs known as: Community Aged Care Packages (CACPs), Extended Aged Care at Home (EACH) packages, and Extended Aged Care and Home Dementia (EACHD) packages.

Originally packages were coordinated by a home care provider, with funding provided by the Australian Government. However in February 2017 this funding (with some exceptions) became available directly to eligible participants enabling them to select services and service providers appropriate to their individual circumstances.

From 1 July 2014, and unlike NDIS, these programs, became means tested and capped. However the Australian Government said "If you received a Home Care Package before 1 July 2014, the new fee arrangements that started on 1 July 2014 will not apply to you. You may continue to be asked to pay the care fees that you already pay". There are also hardship exceptions.

The following four levels of programs were identified:

Home Care Level 1 – to support people with basic care needs.

Home Care Level 2 – to support people with low level care needs.

Home Care Level 3 – to support people with intermediate care needs.

Home Care Level 4 – to support people with high care needs.

Is all of this good enough?

On 20 February 2014 Tony Jones a Policy and Advocacy Officer for Spinal Cord Injuries Australia (SCIA) questioned whether this was good enough. Tony said "According to the Home Care Packages Program Guidelines, aged care packages are targeted at frail, older people with the average age of admission into a package being 81 years. This is precisely the reason why I believe aged care is not easily compatible with the needs of clients with significant and profound disabilities requiring high levels of care.

As stated in the Productivity Commission's 2011 report on Disability Care and Support, a key goal in the disability sector is "enablement"; that is, supports that go toward maximizing the independence and social inclusion of individuals. In contrast, the aged care sector focuses its supports on the end-stage of people's lives. As stated in the report's supporting documents "Forward-looking aspects of life - like job opportunities, owning a house, and living independently from familial carers - are not targets for the aged care system."

<http://www.abc.net.au/rampup/articles/2014/02/20/3947338.htm?site=tropic>

Charter of Rights - Home Care packages

On 1 July 2015 the Australian Government released the Charter of Care Recipients' Rights and Responsibilities – Home Care to ensure that consumers were aware of the Government's expectation that delivery of home care package services must be achieved through an equal partnership between consumer and provider.

Access the February 2017 update

https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/03_2017/charter_-_home_care_-_february_2017.pdf

Commonwealth Continuity of Support (CoS) Programme

Despite the expanded range of services provided under a Home Care Package, serious questions remain about the financial practicability of Home Care Level 4 packages for those with very high disability support needs. This may have been partially addressed with the following announcement.

In August 2016 the Government took a further step in addressing these inequities by agreeing that it is a priority to ensure continuing support for older people with disability who are not eligible for the NDIS. To meet this COAG commitment, the Australian Government will provide continued support to older people with disability who are not eligible for the NDIS either through a new Commonwealth Continuity of Support (CoS) Programme, or through existing aged care programs such as the Commonwealth Home Support Programme (CHSP), if that better suits a client's needs.

The government said that this it will ensure that older people with disability who access specialist disability services managed by states and territories, who are not eligible for the NDIS, will still receive support.

What also remains unclear is the entitlement, especially in NSW, of those aged over 64, who have lost funding access to essential disability support services (wholly or in part) as a direct consequence of State Governments pre-empting the introduction of NDIS and CDC by prematurely withdrawing block funding from many agencies who translated this funding into disability services specific to individual needs.

Establishing your Entitlements to Home Care Packages

The overarching purpose of these packages is to deliver more choice, easier access and better care for older Australians and their families including additional help for carers to access respite and other support. While the Australian Government pays for the bulk of aged care in Australia users may be asked by service providers to contribute to the cost of their care.

When compared with the 'original' range of Home Care plans these new arrangements embrace a wide range of services and supports. The Home Care Packages Programme has been developed to assist older Australians to remain in their homes, particularly targeting frail older people. However, there are no minimum age requirements for eligibility purposes. Support can include, but not restricted to personal care, transport, home modifications, nursing, physiotherapy, meals, household jobs like cleaning and gardening, disability aids, social activities.

How to activate a new Home Care Package

- 1 Register with My Aged Care - Allow at least 10 minutes. You will need your Medicare card. 1800 200 422
- 2 Request an Assessment to discuss your needs/issues and determine your level of eligibility to access a Home Care Package. My Aged Care personnel are not qualified to provide medical advice. Their responsibility is to register your interest and refer your case to an independently qualified assessor. They may seek medical information to assist in linking you to an appropriately qualified assessor. 1800 200 422
- 3 An Accredited Assessor will contact you shortly thereafter to arrange (free of charge) to visit you to discuss your entitlements including how to go about accessing services and your possible financial contribution.
- 4 You may need to also contact Centrelink to determine the level of your financial contribution, if any, to the agreed package. Your Accredited Assessor may be able to provide some guidance. 1800 227 475
- 5 Contact the Service Providers that you feel are best able to address you're agreed needs
- 6 Enter into a formal Home Care Agreement with your selected Service Provider

Reviewing care and Services

All Home Care package recipients have the right to ongoing review of the care and services they receive (both periodic and in response to changes in personal circumstances), and modification of the care and services as required. It is understood that the user contributions that you may make only change if your overall financial circumstances also change. Additionally, if you commenced receiving services prior to 1 July 2014 your contribution is permanently capped.

However there still appear to be some grey areas. For peace of mind it may be worth talking (1800 700 600) to an aged care advocate for advice specific to your individual circumstances. This is a free service.

Many Unanswered Questions

For many, navigating this checkerboard of possible options remains an exercise in untangling bureaucratic red-tape.

Productivity Commission Review of NDIS progress

In June 2017 the Australian Productivity Commission, in an interim report, evaluated the outcomes of NDIS since its inception and put forward a range of draft recommendations to address perceived threats and weaknesses.

In summing up it said "While the issues described may seem considerable, it is important to consider them in the context of the scale, pace and complexity of the NDIS reform. It will take time

to get things right. It is this need for more time that makes the roll out timetable such a key focus for addressing the many and considerable risks identified in this report'

Peter Sullivan, on behalf of

Multiple Sclerosis Network of Care, Australia

<http://www.msnetwork.org>

About Peter Sullivan <http://www.msnetwork.org/bookmarks/peter-sullivan.htm>