



Genetic Support Network of Victoria

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Update on the NDIS

The GSNV welcomed the introduction of the National Disability Insurance Scheme (NDIS) in 2013. Although we do not view genetic conditions as a disability, conditions with a genetic basis tend to be complex and chronic, and people and families living with genetic conditions may need some supports. The GSNV is excited that the Barwon region is a launch site in Victoria and we hope that the implementation of the NDIS is a first step in helping to ensure that people living with genetic conditions are provided with the support and assistance they need to live their best life.

To date, all states and territories have now signed on to the NDIS, with the Western Australian State and Australian Federal Governments recently reaching an agreement to launch in Western Australia in July 2014. In this article, we have tried to answer some of the common questions around the implementation of this scheme.

What is the NDIS?

The National Disability Insurance Scheme (NDIS) arose from an investigation by the Productivity Commission in disability system reform led by Prime Minister Kevin Rudd in 2009. The Productivity Commission investigated the unmet needs of people with a disability and their families and carers across Australia, and analysed high-functioning support systems overseas. The GSNV made a formal submission to the Productivity Commission in 2010 on behalf of its members and community stakeholders. In July 2011, the NDIS was recommended and was passed through Federal Parliament on 21 March 2013.

NDIS was launched on the 1st of July 2013 and replaces all previous state and territory disability systems. It will cover 460,000 Australians (at any given time) with disability and their families, which is more than double the number that were previously covered.

All Australians will be covered by this scheme, which aims to fund long-term high quality care and support (excluding income replacement) for people with significant disabilities.

The NDIS is a person-centred support system that will empower Australians with a disability and their families take control of their lives, achieve their goals and participate in social and economic life. It will focus on early intervention and the provision of appropriate aids, equipment, training and development that produce the best long term outcomes. It will provide assistance at the right time, rather than only once people reach crisis.

Last updated: August 2013, Genetic Support Network of Victoria

What will change under the NDIS?

Australia's previous disability support system was inequitable. It provided no certainty around future support and people received differing levels of support depending on how and when their disability was acquired. The new system is entitlement-based and aims to help people choose what is best for them. Disability support is reframed under the NDIS, in that it is an investment and a driver of systemic and cultural change, which will shift the way we think about support for people with disability. People are provided with individualised packages that include the ability to choose their own service agencies. This means that people can employ the support workers they want or choose from pre-packaged supports from specialists and mainstream providers. The new system will also provide access to and help from intermediaries who can assist people to make choices and handle administrative tasks around their support package. Alternatively, people can opt to cash out their package and purchase their own supports.

The NDIS focuses on the provision of early interventions, especially if there is good evidence that it will significantly slow down or stop decline in function. It also takes the financial and management pressure off individuals and will hopefully help people avoid reaching crisis.

What won't change under the NDIS?

The NDIS as a system will not be responsible for the following:

- Diagnosis and clinical treatment of health conditions
- Activities that aim to improve the health status of Australians (including GP services, dental care, nursing, etc)
- Time-limited therapies such as rehabilitation or post-acute care
- Palliative care

These services will remain under the current healthcare system through Medicare.

Furthermore, the NDIS does not replace the need for healthcare, income or life insurances. These policies are still very important for the majority of Australians in the event of temporary illness, surgery, loss of work due to injury and sudden or accidental death.

Who and what will be covered by the NDIS?

The aim of the scheme is for all Australians to be covered, because disability can affect anyone at any time. To date, all states and territories have signed up for the scheme. In

order for a person to be eligible for support, they would need to have a permanent disability and meet one of the following conditions:

- Have significant limitations in communication, mobility and self-care
- Have an intellectual disability
- Have a condition for which early intervention would result in an improved level of functioning
- Be a person for whom intervention would have significant benefits

The Productivity Commission have also suggested that people with a disability who do not meet the above criteria are to be provided with information and linkages to appropriate services and supports. For those that apply but are unsuccessful, there is also an internal review and appeals process and the option to appeal to the Administrative Appeals Tribunal (<http://www.aat.gov.au/AboutTheAAT.htm>).

Supports that will not be funded include those that:

- are likely to cause harm to the participant or pose a risk to others;
- are unrelated to the participant's disability;
- duplicate other supports provided under alternative funding;
- are part of the day-to-day living expenses that are incurred by the general public (for example rent, groceries, household bills) and are not related to disability support needs; and
- are related to income replacement.

Will people with disability over the age of 65 be covered?

People who acquire a disability under the age of 65 will have the choice when they turn 65 to remain under the NDIS system or instead transition into the aged care system. Moving into the aged care system will be of benefit to individuals who want/need to be cared for in an aged care facility.

People that acquire a disability after the age of 65 will not be able to access the NDIS but can instead access the aged care system.

Will carers be funded through the NDIS?

Individuals who are funded directly by the NDIS are able to allocate and spend money on services and supports that meet their needs. These plans may include arrangements to reimburse carers in some instances. Ultimately the NDIS will make decisions on what may be included in a plan.

What supports will be available through the NDIS?

- Aids, equipment, home and vehicle modifications

Last updated: August 2013, Genetic Support Network of Victoria

- Personal care
- Support for community inclusion
- Respite
- Specialist housing support
- Domestic assistance
- Transport assistance
- Therapies
- Guide and assistance dogs
- Case management and coordination
- Specialist employment services
- Crisis/emergency support

Will the roll out of the NDIS affect the Disability Support Pension?

The NDIS and the Disability Support Pension (DSP) are different systems. The DSP is about income support, the NDIS is about removing challenges to people with disabilities through appropriate support. The NDIS has no relation to the DSP and will not affect the DSP in any way.

Roll out schedule:

ACT

- Launch site – Covers all ACT, starts 1 July 2014 for 2,500 participants
- Full site – Starts 1 July 2016 with full coverage by 2019

NSW

- Launch site – Hunter region starts 1 July 2013 for 10,000 people
- Full site – Starts 1 July 2016 with full coverage by 2018

NT

- Launch site – Barkly region starts 1 July 2014 for 100 people
- Full site – no current agreement as yet

Qld

- Launch site – No current agreement as yet
- Full site – Starts 1 July 2016 with full coverage by 2019

SA

- Launch site – For participants aged 0-14 starts 1 July 2013 for 5,000 people
- Full site – Starts 1 July 2016 with full coverage by 2018

Tas

- Launch site – For participants aged 15-24 starts 1 July 2013 for 1,000 people
- Full site – Starts 1 July 2019

Vic

- Launch site – Barwon region starts 1 July 2013 for 5,000 people
- Full site – Starts 1 July 2016 with full coverage by 2020

WA

- WA signed onto the scheme on 4 August 2013
- WA will trial two systems from 2014/15. The previous system 'My Way' will continue in the South West region and the Kwinana-Cockburn area. My Way allows people

with a disability to select the services they want from mostly not-for-profit organisations. The Commonwealth's system will be trialled in Midland, the Perth Hills area and adjoining suburbs.

What will the NDIS cost?

The scheme will cost \$22.2 billion a year when it is fully operational in 2019-20.

The Federal government will provide 53% or \$11.7 billion of the funding for the scheme when it is fully operational.

The NSW government will have to provide an extra \$3.2 billion towards the scheme in that year, Victoria more than \$2.5 billion, Queensland more than \$2 billion, South Australia \$750 million, Tasmania \$230 million, the ACT \$170 million and the Northern Territory \$100 million.

The WA government will fund 60% of the cost of their trial, while the federal government will fund the remaining 40%.

It will also be funded in part by a rise in the Medicare levy from 1.5% to 2% from July 2014 that will raise \$20.4 billion between 2014-15 and 2018-19.

How much extra will I pay?

To help fund the scheme, the Medicare levy has been increased from 1.5% of taxable income to 2% from July 2014. The money raised will be placed in a special fund to support the NDIS.

The annual cost to taxpayers will be:

- About \$150 extra for those earning \$30,000
- About \$350 extra for those earning \$70,000
- About \$550 extra for those earning \$110,000

Why should I have to pay extra tax to fund this insurance program?

The NDIS benefits all Australians; if you or any of your loved ones ever acquire a permanent disability through injury or develop an ongoing condition (genetic or otherwise), they will receive the support they need to be able to work towards life goals and continue to have a meaningful and fulfilling life within the community.

How will the NDIS impact on people with genetic conditions?

There are some important 'take home' messages regarding the NDIS:

Last updated: August 2013, Genetic Support Network of Victoria

1. Eligibility depends on FUNCTION not on DIAGNOSIS

This point is quite crucial for those affected with undiagnosed genetic conditions or syndromes without a name. NDIS eligibility is dependent on the following:

- Disability, age and residency requirements
- Disability being permanent
- Reduced level of function with regards to self-care, communication, mobility or self-management OR if early intervention is cost effective and significantly improves outcomes

2. To be eligible for the NDIS, one must be UNDER the age of 65 years

As already stated, if you have access to the NDIS before the age of 65, then it is your choice once you reach 65 years of age as to whether you stay under the NDIS or move to the aged care system.

Most genetic conditions have an onset before the age of 65 years and so hopefully the age eligibility criteria for DisabilityCare will not affect many families impacted by genetic conditions. However, the healthcare system is already designed to look after individuals over 65 years of age who need assistance through the aged care system.

3. The NDIS DOES NOT replace the need for income, health or life insurances

The NDIS is a system set up to help empower individuals and families with disability take control of their lives. The system will not replace lost income, pay for surgeries or the loss of a loved one. It is therefore important that income, life and health insurances are still taken out by individuals and families affected by genetic conditions.

4. If you are unsure whether you or someone you care for is eligible for the NDIS you can use My Access Checker (<http://www.disabilitycareaustralia.gov.au/my-access-checker>) to find out or you can call on 1800 800 110 or visit <http://www.disabilitycareaustralia.gov.au/about-us/contact-us>

References and further information

http://www.adhc.nsw.gov.au/about_us/strategies/national_disability_insurance_scheme

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Last updated: August 2013, Genetic Support Network of Victoria

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<http://www.abc.net.au/pm/content/2013/s3792183.htm>

<http://www.illawarramercury.com.au/story/1658390/ndis-gets-thumbs-up-from-carers/?cs=320>

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