NDIS | Securing support Achieving independence

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Every Australian Counts

NDIS | Revolutionising disability services

Submission on the National Disability Insurance Scheme Bill 2012 - on behalf of the Every Australian Counts Campaign

Contact:

The Hon. John Della Bosca

National Campaign Director

Every Australian Counts campaign for the National Disability Insurance Scheme

> *"Every human being has a basic right to maximise their abilities and thereby contribute to society to their full capacity. It is the responsibility of the whole of society to ensure that this happens, as we will all benefit. NDIS makes good economic sense, in addition to the obvious social benefits."* ACT resident Submission

Every Australian Counts is a national, grassroots campaign advocating for the implementation and sustainable funding of the National Disability Insurance Scheme (NDIS). The campaign has reached out across the country over the last two years, uniting people with disability, their families and carers, and disability service and support organisations, amplifying their voices to ensure disability no longer means invisibility.

The Every Australian Counts campaign has supported over 150,000 ordinary Australians with and without disability to fight together for a smarter, fairer system of support for any Australian who is born with, or acquires a disability that affects their ability to participate in daily life.

In April 2012, over 35,000 Every Australian Counts campaigners held public rallies in six capital cities across Australia to demonstrate strong support for the NDIS. Campaigners also held thousands of events in homes, workplaces, shopping centres and community centres to raise public awareness of the urgent need for the NDIS to provide supports to people with disability so they have the same right to participate in the community as anyone else.

In its second year, a campaign event known as DisabiliTEA 2012 became the largest disability event the nation has seen. Every Australian Counts campaigners continue to lobby for change following the announcement of five NDIS launch sites, to ensure the NDIS progresses to a full funding commitment across all states and territories, as recommended by the Productivity Commission.

Nationally, NDIS supporters have continued a relentless campaign of phone calls, letter-writing, emailing, media engagement and social media communication to spread the message and ensure every politician, in every state and territory got the message: **Australia needs the NDIS.**

The need for the NDIS strikes at the core of what most Australians hold dear – a fair go. For a nation as wealthy as Australia, to have 45 per cent of Australians with disability live in or near poverty is simply not acceptable and has to change. One of Australia's best known sporting legends recently challenged Australians to acknowledge this and support the NDIS:

> *"We have to ask how we can function as a light to those around the world when we continually fail to provide the support and services to those who need it most within our own communities."* Kurt Fearnley

In his inspiring Australia Day 2013 Address, Paralympian gold medallist, marathon racer and Australia Day Ambassador, Kurt Fearnley, clearly articulated the view of hundreds of thousands of Australians with disability, their family members, carers and supporters, as he called on every Australian to support the NDIS.

The call for the disability reform that can offer real hope, to bring real change and transform lives of Australians with disability has never been louder.

The NDIS is a needs-based funding mechanism which will pay for person-centred disability supports. It will improve the economic and social participation of Australians with disability, their families and carers throughout their lives, regardless of where they live or how the person acquired their disability.

Example Campaign Material

Every Australian Counts campaigners in every suburb, town, region and city of Australia have worked together with determination and passion to ensure their elected federal and state Members of Parliament and Senators know that the NDIS is a once in a generation opportunity that they need to understand, uphold and enshrine within Australian law.

Australia's political leaders should be proud of how their support for the NDIS has brought the nation to this historic point, with the National Disability Insurance Scheme Bill 2012 scheduled to become law in 2013. Equally our political leaders should acknowledge that there is no turning back from the evidence that Australians with disability are living as second class citizens. The historic reform of fully implementing a sustainable NDIS, which places the needs and choices of people with disability at its heart, in every State and Territory must take place as soon as possible.

Kurt Fearnley, 2013 Australia Day Address http://www.australiaday.com.au/whatson/australiadayaddress2.aspx?AddressID=34

Understanding the Every Australian Counts campaign submission to the Senate Inquiry

Every Australian Counts has campaigned for the NDIS under the authority of the National Disability and Carer Alliance. The alliance consists of the three peak bodies in the disability sector, National Disability Services, Carers Australia and the Australian Federation of Disability Organisations.

The Every Australian Counts campaign has engaged and enabled people with disability and those who support them across Australia to play an active role in the creation of the NDIS. We have continued these efforts in relation to this inquiry by assisting our campaigners to express their views about how the NDIS should look and operate. To this end, the Every Australian Counts campaign provided an online mechanism for people to submit their views about the draft NDIS Bill to the Senate Inquiry.

At the time of drafting this submission more than 1300 Australians had used the Every Australian Counts website to make a submission to this Senate Inquiry.

To aid the Senate's deliberations, the Every Australian Counts submission highlights the most popular key features and general community expectations represented in submissions sent though our website to this senate inquiry. This is intended to help the Committee understand the 24/7 challenges faced by people with disability and their families.

A broad spectrum of community members submitted their views on the NDIS Bill via Every Australian Counts, including people with disability, their families and carers, teachers, doctors, nurses, allied health professionals, service providers, advocates and concerned friends who want to see the NDIS work in the spirit it was intended:

that the NDIS legislation will enshrine Australians' rights for disability support of their choice which meets their needs in their communities of choice.

The Every Australian Counts campaign asked our supporters to answer four questions in making a submission to this inquiry. A copy of the online submission form can be seen in appendix one of this submission.

A snapshot of comments by Every Australian Counts campaigners to the NDIS Bill 2012 Senate Inquiry

ACT	"The system doesn't work for our family because services are so fragmented, tied up in what they need to achieve not what we (families) require, have untrained staff who don't know or understand our needs and mostly only offer band-aid solutions. Having a dual disability with a mental health condition just makes it worse with mental health services refusing to provide services because they say it is better placed with disability services but disability services have no training or funding to assist with the mental health aspect of someone with a disability. So that leaves families NO WHERE and WITH NO ASSISTANCE."
	"Every human being has a basic right to maximise their abilities and thereby contribute to society to their full capacity. It is the responsibility of the whole of society to ensure that this happens, as we will all benefit. It [NDIS] makes good economic sense, in addition to the obvious social benefits."
VIC	"Because good services are almost impossible to get, and then you feel almost privileged to be funded for something even if it is not exactly what you need or would choose. You are never free to have services that are completely tailored to what you actually need. There are year long waiting lists for services and accommodation. The sector is crisis driven and services are ad hoc. DHS offer caravan parks as suitable housing for intellectually disabled people. Disabled people's legal rights are not upheld and abuse of all sorts is rife."
	"As the sister of a young person with a profound disability, I have grown up watching my family sort through broken and non-existent disability services looking for supports for my brother. As my brother gets older, it becomes more obvious that the supports and services he will need into the future currently do not exist. We cannot access services in a timely manner. We are on a waiting list that seems to have no end and as a result cannot obtain any funding to utilise services that do exist. My brother deserves to participate in his local community and this is not possible without funding and support".
NT	"The support types and features of the Scheme will need to be flexible to cater for diverse needs but not encourage rorting or inefficiency, a big challenge! Person centred approach that encourages individual and family growth, capacity and responsibility is needed along with a national approach to life that emphasizes social accountability and addresses the social determinates of health".

NSW	“As a physiotherapist I come in contact with a lot of disabled persons. I have worked in the UK in a spinal unit & was impressed with the service they have in that country. I am amazed at the lack of facilities in this "lucky" wealthy country where they are treated like second rate citizens”.
	“We have a young daughter who has severe cerebral palsy. The system to support her is disjointed and has crazy age limitations (CP is not going to be "cured" by age 7). There is not enough therapy support, slow equipment support (and prohibitively expensive), and long waitlists for essential services. Respite is hard to get and haphazard if it does come. Funding that may be in place at school age has to be applied for repeatedly, and then stops at 18. Then the whole process needs to be started again. This means over administration, red tape and high costs. The new system needs to be streamlined, and funding given to the parents or carers who are trusted, well-informed and will do everything in the their power to make their loved ones supported, comfortable and able to achieve their personal goals. Other countries get it right, how come Australia is SO SLOW on the uptake?”.
QLD	“Inadequate resources to support their children preclude two of my friends who have severely disabled children from going to work and both contributing their significant skills to our community and economy, as well as enabling themselves to earn an income that supports their independence”.
	“The disability system is disempowering in that it takes so long for any resolution to occur because of the paperwork we go through and the time delays for any funding to come through. There are also few meaningful work opportunities or lifestyle programs for a person with a disability to be engaged in”.
TAS	“If the NDIS will not go ahead, there is no future for my child. She will not receive the education that she requires for an independent life, she will not participate in social activities, she will not gain meaningful employment and she is likely to live with us for a long time to come”.
	“Most importantly – I am very tired of those who 'know' what we need! In all of my 25 years of caring for a profoundly disabled daughter, not once have I ever been asked 'what is it you need to be able to care for your daughter at home and what do you see as your requirements into the future'. In short a serious lack of consultation with stake holders”.

Support needs met by the disability system

Support needs not met by the disability system

WA	“My husband and I work full time, our son finished school in December 2012 and was given funding for 10 hours of Alternatives to Employment funding. On appeal we got a further 5 hours. I work 40 hours per week, what am I supposed to do with my disabled son for the 25 hours that he has no funding for? Am I supposed to stop working? We have a mortgage and bills to pay and have always worked hard to support our son and provide him and our daughter with good education and opportunities. We have never been reliant on any system but now we need support! and 40 hours of it. My son can’t be at home by himself. I'm at my wits end with the disability system and the lack of support and opportunities for children after school”.
	“We have been caring for our 32 year old son with cerebral palsy full time. We are now 60 years old and have had no life outside our home. My husband relies on pain killers for his back problems, so that he can continue to lift C, who is an average sized man. Cs cannot speak, walk or carry out any self care. The disability system is failing because we have been applying for accommodation support funding for five years without success, and no hope of receiving it because to be in 'critical need' and deemed eligible, we need to be divorced, one of us to have a terminal illness, or be aged 80 years or over. In the last 6 months I can feel myself cracking. C doesn't have the quality of life he deserves because we are too exhausted to take him out, and I am often impatient with him (he is very alert) I lay awake at night worrying about his future when we die”.
SA	“Working as a paediatric physiotherapist in regional South Australia, I am all too familiar with the extreme difficulty we have in accessing mobility and access equipment for our children with major needs. All too often despite the best forward planning many of our children have to start kindergarten in a pusher because the wheelchair which has been on request for 12 to 18 months is not available! How demoralizing and what a poor first image! The difficulty of transporting equipment from kindergarten to home or school to home, particularly when there are other children in the family can also be quite prohibitive. We all know the importance in early development of the ability to make choices and the consequence of our decisions, but how can these children learn this if they must rely on someone to move them if they have time”.
	“This isn't about luxury or extras this is about fundamental care and service - people should not be begging for what many of us consider human rights”.

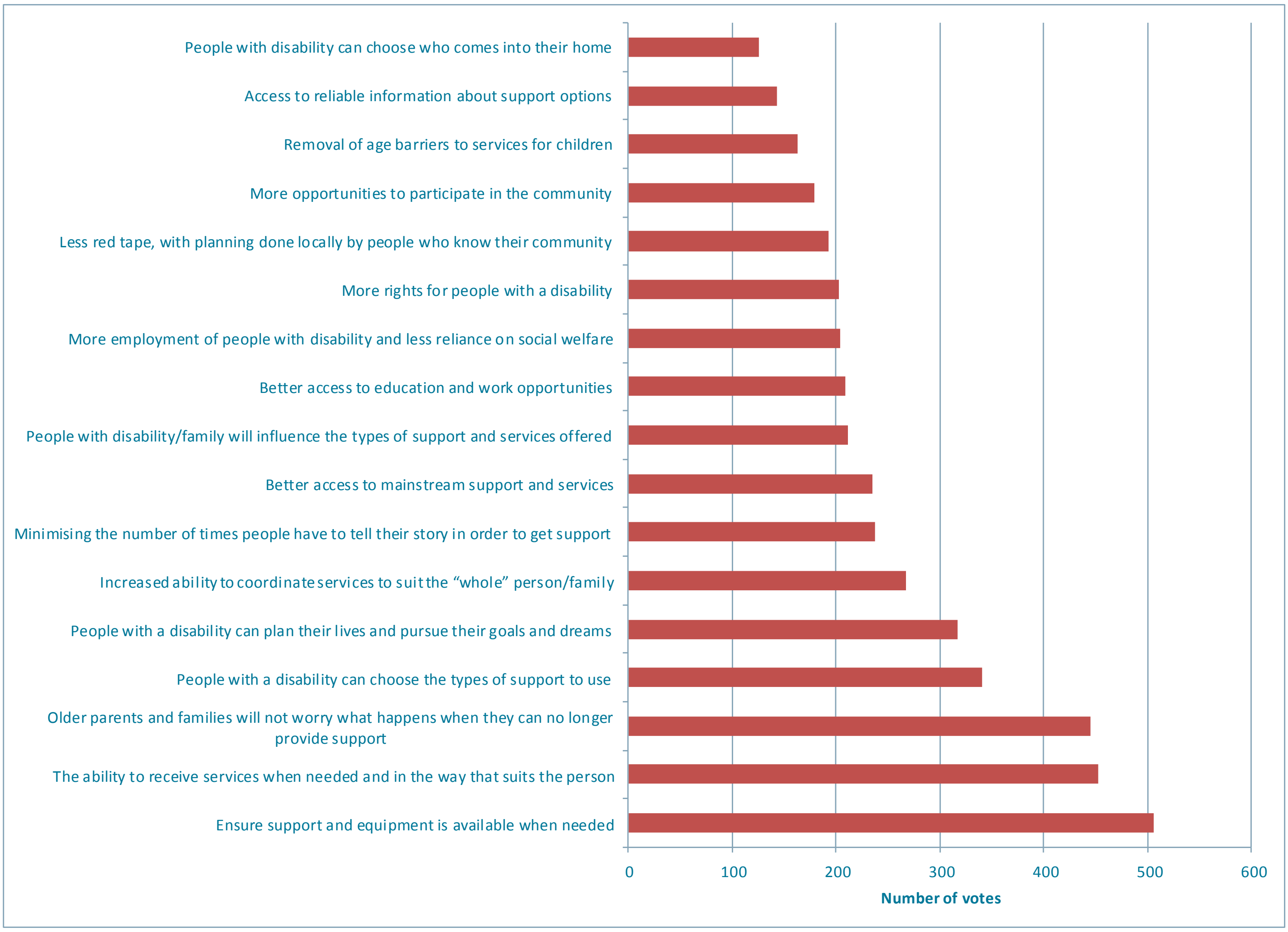
Key findings to questions

Which three features of the NDIS will have the biggest community impact?

Analysis of submissions received by Every Australian Counts from across Australia highlights that the three features of the NDIS which will have the biggest community impact are:

- ⇒ Ensure support and equipment is available when needed
- ⇒ The ability to receive services when needed and in the way that suits the person
- ⇒ Older parents and families will not worry what happens when they can no longer provide support

The chart below displays the full list of answers ranked by their votes:

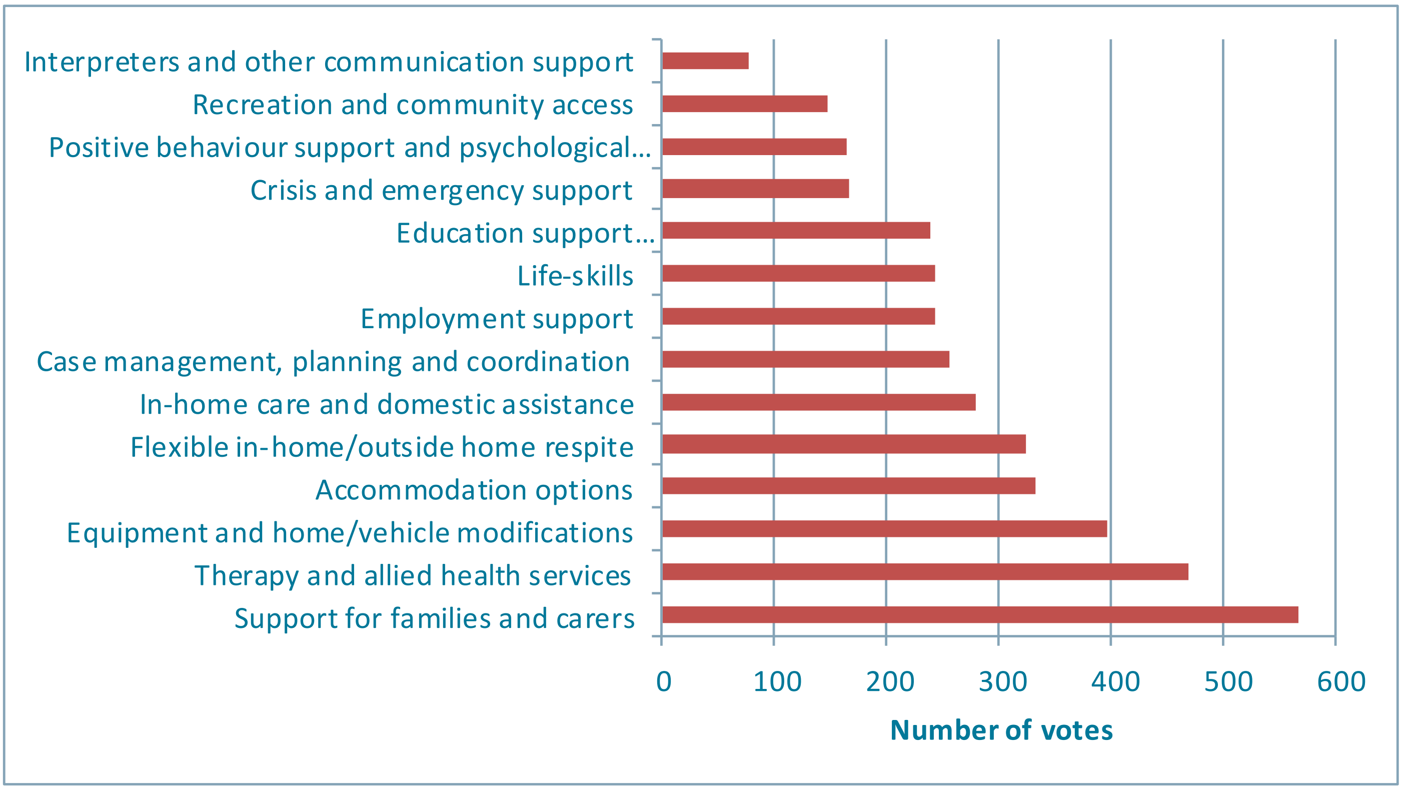


Which of the three support types are the most important for the NDIS to provide?

Analysis of submissions received by Every Australian Counts from across Australia highlights that the three support types that are the most important for the NDIS to provide are:

⇒ Support for families and carers
⇒ Therapy and allied health services
⇒ Equipment and home/vehicle modifications

The chart below displays the full list of answers ranked by their votes:



Summary

These submissions continue to highlight how the severe underfunding of disability services has a punitive financial effect on people with disabilities and their families as well as the nation as a whole.

Without adequate support, equipment and services, people with disability are not able to carry out the most basic of human tasks, like getting up and showering, getting meals and transport, which of course restricts their ability to maintain any kind of working or community life.

Furthermore it almost always requires family (where available) to fill the gap of service provision and the time consuming task of dealing with the disability system, so often by foregoing their own career and the monetary and social benefits this brings. Families are forced to the brink of poverty and despair resulting in broken relationships, and a cycle of poverty and mental health issues. Where funding and services are provided, there is a constant theme of wasted resources and inflexibility that does not assist the person with disability towards independence and productivity.

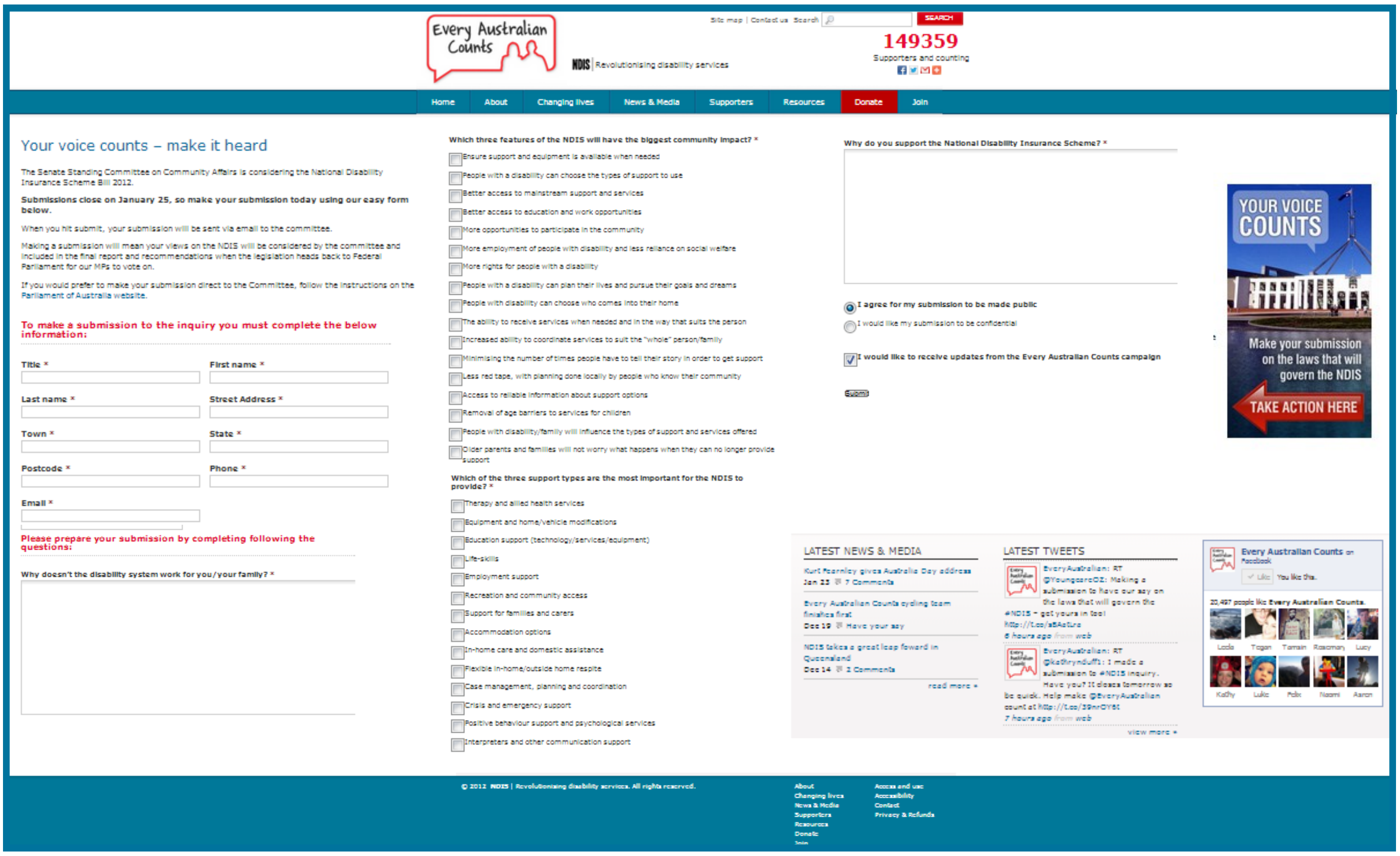
The submissions received by Every Australian Counts continually cite the missed opportunities when timely support is denied including key milestones in gaining independence such as the ability to speak or to move independently or study or work.

They also reiterate the difficulties in having a say in the best kind of equipment or service provision. Again, these factors are key in ensuring that people with disability and those who support them are able to participate fully in all aspects of the Australian community and to contribute to it economically, culturally and socially.

The third major finding is the terrible uncertainty for people with disability and their ageing parent-carers or family over future accommodation and support. Parents and siblings report never-ending worry over the lack of options for their loved ones, with the only certainty being that they will be alone and immensely vulnerable.

It is with the support of the Every Australian Counts campaign that these factors are bought to the attention of Senate Inquiry Committee when considering issues in relation to the National Disability Insurance Scheme Bill 2012.

Appendix one - The online submission form used by the Campaign



Your voice counts – make it heard

The Senate Standing Committee on Community Affairs is considering the National Disability Insurance Scheme Bill 2012.

Submissions close on January 25, so make your submission today using our easy form below.

When you hit submit, your submission will be sent via email to the committee.

Making a submission will mean your views on the NDIS will be considered by the committee and included in the final report and recommendations when the legislation heads back to Federal Parliament for our MPs to vote on.

If you would prefer to make your submission direct to the Committee, follow the instructions on the Parliament of Australia website.

To make a submission to the inquiry you must complete the below information:

Title *

First name *

Last name *

Street Address *

Town *

State *

Postcode *

Phone *

Email *

Please prepare your submission by completing following the questions:

Why doesn't the disability system work for you/your family? *

Which three features of the NDIS will have the biggest community impact? *

- ☐ Ensure support and equipment is available when needed
- ☐ People with a disability can choose the types of support to use
- ☐ Better access to mainstream support and services
- ☐ Better access to education and work opportunities
- ☐ More opportunities to participate in the community
- ☐ More employment of people with disability and less reliance on social welfare
- ☐ More rights for people with a disability
- ☐ People with a disability can plan their lives and pursue their goals and dreams
- ☐ People with disability can choose who comes into their home
- ☐ The ability to receive services when needed and in the way that suits the person
- ☐ Increased ability to coordinate services to suit the "whole" person/family
- ☐ Minimising the number of times people have to tell their story in order to get support
- ☐ Less red tape, with planning done locally by people who know their community
- ☐ Access to reliable information about support options
- ☐ Removal of age barriers to services for children
- ☐ People with disability/family will influence the types of support and services offered
- ☐ Older parents and families will not worry what happens when they can no longer provide support

Which of the three support types are the most important for the NDIS to provide? *

- ☐ Therapy and allied health services
- ☐ Equipment and home/vehicle modifications
- ☐ Education support (technology/services/equipment)
- ☐ Life-skills
- ☐ Employment support
- ☐ Recreation and community access
- ☐ Support for families and carers
- ☐ Accommodation options
- ☐ In-home care and domestic assistance
- ☐ Flexible in-home/outside home respite
- ☐ Case management, planning and coordination
- ☐ Crisis and emergency support
- ☐ Positive behaviour support and psychological services
- ☐ Interpreters and other communication support

Why do you support the National Disability Insurance Scheme? *

● **I agree for my submission to be made public**

○ I would like my submission to be confidential

☑ **I would like to receive updates from the Every Australian Counts campaign**

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Text from the Online submission form:

Question 1 — Why doesn’t the disability system work for you/your family?

Question 2 — Which three features of the NDIS will have the biggest community impact?

- Ensure support and equipment is available when needed
- People with a disability can choose the types of support to use
- Better access to mainstream support and services
- Better access to education and work opportunities
- More opportunities to participate in the community
- More employment of people with disability and less reliance on social welfare
- More rights for people with a disability
- People with a disability can plan their lives and pursue their goals and dreams
- People with disability can choose who comes into their home
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- Access to reliable information about support options
- Removal of age barriers to services for children
- People with disability/family will influence the types of support and services offered
- Older parents and families will not worry what happens when they can no longer provide support

Question 3 — Which of the three support types are the most important for the NDIS to provide?

- Therapy and allied health services
- Equipment and home/vehicle modifications
- Education support (technology/services/equipment)
- Life-skills
- Employment support
- Recreation and community access
- Support for families and carers
- Accommodation options
- In-home care and domestic assistance
- Flexible in-home/outside home respite
- Case management, planning and coordination
- Crisis and emergency support
- Positive behaviour support and psychological services
- Interpreters and other communication support

Question 4 — Why do you support the National Disability Insurance Scheme?