Implementation and Performance of the National Disability Insurance Scheme in the Australian Capital Territory



A Submission

to the

ACT Legislative Assembly
Standing Committee on
Health, Ageing and Social Services

from the

ACT Disability Reference Group

30 March 2018

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ABOUT THE ACT DISABILITY REFERENCE GROUP

The ACT Disability Reference Group (DRG) advises the ACT Government on matters of public policy affecting people with disability in the ACT. We advise Government on ways the ACT can be a more inclusive community for all people with disability.

DRG members – who are appointed for a term of two years by the ACT Minister for Disability, Children and Youth -- draw on their personal or professional experience as people with disability, family members, carers, peer supporters, advocates or service providers to provide timely, informed, and independent advice to Government.

The DRG also helps the ACT Government to implement its commitment to advance Australia's National Disability Strategy 2010-2020. The ACT commitment is known as INVOLVE: Canberra Disability Commitment

For more information about the Disability Reference Group, go here:

http://www.communityservices.act.gov.au/disability_act/disability-reference-group

ABOUT THE DRG SUBMISSION

Reflecting our purpose to draw on community connections to advise Government, we took a consultative approach to gathering material for this submission. It is a synthesis of feedback from many sources.

- We conducted an online survey focusing on experiences and opinions of NDIS participants the Canberra. The full results of that survey are given in appendix 2 of this submission.
- We hosted a four-hour long drop-in session for anyone who wished to attend to share their experiences of the NDIS in the ACT.
- We organized an online forum through the INVOLVE Facebook page to coincide with our drop-in session.
- Members attended a range of public consultations about the Legislative Assembly's inquiry hosted by other community organisations in the ACT.
 Our role was to listen to what people said.

- We sought feedback from key peak disability, carer and community organisations.
- We drew on the networks of DRG members.
- We reviewed previously-prepared relevant documents, primarily the Productivity Commission's study in late-2017 *National Disability Insurance Scheme (NDIS) Costs*¹, quarterly reports published by the National Disability Insurance Agency (see appendix 1), and other resources.

¹ https://www.pc.gov.au/inquiries/completed/ndis-costs#report

DRG RECOMMENDATIONS

This document contains many suggestions and recommendations within its different sections. We urge the ACT Government and the NDIA to read the detail, act to put in place those ideas that can be implemented quickly and consider how longer terms changes – consistent with these and good ideas in other submissions -- could be introduced as soon as practicable.

The recommendations in this section summarise more detailed ideas that readers will find in the pages that follow.

DRG Recommendation 1

The Standing Committee on Health, Ageing and Social Services should request explanations from the ACT Government and the NDIA about the following data in quarters 1 & 2 2017-2018 NDIA Quarterly Reports:

- The disproportionately high proportion of the national total of participants exiting the NDIS who live in the ACT.
- The growth in the number of ACT participants exiting the NDIS as reported quarter to quarter.
- Reasons for the increase in the numbers of children in the ACT exiting the NDIS.

DRG Recommendation 2

The ACT Government and the NDIA in the ACT should develop a partnership approach with ACT organisations of Indigenous Australians to develop an ACT strategy to promote greater understanding and uptake of the NDIS by Indigenous people with disability.

DRG Recommendation 3

The ACT Government and the NDIA in the ACT should develop a partnership approach with ACT organisations of culturally and linguistically diverse people to develop an ACT strategy to promote greater understanding and uptake of the NDIS by people with disability from culturally and linguistically diverse (CALD) backgrounds.

DRG Recommendation 4

The ACT Government should continue to support and develop *INVOLVE Canberra*, the ACT commitment to the National Disability Strategy. The reinvigorated strategy would benefit from even greater involvement by people with disability, family members and carers, and the broader ACT disability sector. The strategy should be adequately-funded and seek partners and champions in the ACT business community.

DRG Recommendation 5

The ACT Government and the NDIA should act urgently together to identify and eradicate unintentional and restrictive interface barriers between different mainstream support services and the NDIS. The two tiers of government should draw on the information, examples and solutions proposed in this and other submissions to the inquiry.

DRG Recommendation 6

The NDIA be more responsive to user needs, in relation to participant feedback on access, information, waiting times, transparency of decisions and plan design and delivery.

DRG Recommendation 7

The ACT Government should require all government departments to develop and review regularly Disability Inclusion Action Plans. The first iteration of approved plans should be in place by 30 June 2019.

DRG Recommendation 8

The ACT Government should continue to support and adequately resource the Office for Disability as a strategically important entity within government, in its relations with the NDIA and across the wider Canberra community.

IMPLEMENTATION AND PERFORMANCE OF THE NDIS IN THE ACT

Introduction

The National Disability Insurance Scheme is an essential and long-overdue reform. People with disability, family members, and the specialist disability services sector wholeheartedly support the idea of the NDIS. The scheme matters. The human rights and social inclusion principles that guide it are important. And the potential of the NDIS to transform people's lives for the better (not only the 475,000 participants with plans) makes it vital we get the scheme right: timely, efficient, effective and good value for money.

It is not PR rhetoric to say the NDIS truly does have the potential to be a social (and economic) policy reform as important as Medicare or the introduction of compulsory superannuation. The NDIS is a 'good thing' and we support it.

The DRG also recognize that the scheme remains an enormous 'work in progress'. That is not a negative criticism but a statement of fact, which is sometimes overlooked or forgotten.

The idea that by now everything could be or should be working entirely problem-fee is simply not realistic, considering it is:

- a \$22 Billion reform,
- creating almost half a million new individual customers / clients / participants,
- involving the reconfiguration of many, many different departments, agencies and programs across every government in Australia,
- and requiring the total re-organisation of the disability support industry,
- including doubling and wholly transforming the work force,

and it is still less than the five years since the NDIS was launched on 1 July 2013.

Broadly speaking, therefore, the disability community in the ACT understands and accepts change is difficult and takes time. But that does <u>NOT</u> mean:

- there are no problems that don't need to be or cannot be fixed now,
- there is no room for improvement as we proceed, or that
- we can't all be smarter, quicker, a bit more agile and willing to work together to help the NDIS live up to its initial promise and become the best disability support system it has the potential to be.

But even as we commit ourselves to building the best NDIS for the future, it is vital the NDIS works well today. NDIS participants already in the scheme must receive high quality service from the NDIA, its contracted intermediaries and the intergovernmental agreements that set the framework for the NDIS.

The qualitative feedback the DRG has received and the data we reproduce below clearly show that this is not always so. We can and must do better.

There is a lot about the NDIS that is good. But it is not perfect. There is room for improvement in outcomes for participants, better performance by the NDIA, and more effective policy and operational settings between the NDIS and other service systems – the mainstream -- that we all make use of (education, employment, health, housing, transport, etc.).

The DRG submission should be read in that vein. We support the concept of the NDIS. As friends and allies we celebrate its successes. And as friends and allies we say the NDIS has room for improvement so it can function more effectively. There is no contradiction in that constructive criticism.

Headline ACT News from Recent NDIA Quarterly Reports

The DRG is pleased to acknowledge progress and thank everyone who has contributed to important areas of NDIS development and growth. But as some of the headline reports below indicate, there are also grounds for concern about key indicators of social inclusion (or exclusion).

- It is good news and a remarkable achievement that 6,459 NDIS plans (including 21 in this quarter through the ECEI Gateway) had been approved in the ACT by 31 December 2017. (Compared to the initial bilateral agreement estimate of 5,075.)
- We note, however, that after subtracting participants who exited the scheme during the quarter, the number of NDIS participants in the ACT with an active plan on 31 December 2017 was 6,078. This is a net increase of only 57 participants when measured against the corresponding figure (6,021) for the ACT on 30 September 2017.
- DRG Members expressed surprise that the number of approved ECEI
 Gateway approved plans is / was not higher. We would like to know more.
- Similarly, the DRG is interested to know more about the seemingly increasing numbers and percentages of ACT participants, children in particular, exiting the scheme:
 - The previous quarterly report (to 30 September 2017) reported that
 283 ACT participants in that quarter exited the scheme.
 - 17.7% of all participants exiting the NDIS in this quarter (1,597) were ACT participants. In the same quarter, ACT participants constituted only 5.1% of the national total.
 - The most recent quarterly report (to 31 December 2017) puts the number of ACT participants exiting the scheme at 381; a 34.6% increase on the previous three months.
 - 16.6% of all participants exiting the NDIS in that quarter (2,288) were ACT participants. But by 31 December 2017, the proportion of ACT participants in the fallen to 4.3% of the national total.

- Both quarterly reports note "The ACT has undertaken a review of participants with Early Intervention access type to determine potential to exit, and as a result a high number of children were exited from the Scheme." 2
- The DRG would welcome a clear picture from the NDIA and / or the ACT Government that satisfactorily explains:
 - Quarter on quarter, why is the rate of exiting the NDIS in the ACT accelerating while the rate of joining the scheme in the ACT is slowing down and / or stabilizing (253 approved plans in Q1 against 139 in Q2)?
 - And why, as the NDIS grows towards full scheme across the country, are ACT exits from the scheme at least 4 times greater than proportion of all participants?
 - We acknowledge that the NDIS is to all intents and purposes in 'full scheme' mode in the ACT but these patterns of exiting and entering, and the comparatively high percentages of exits in the ACT compared to the national total would benefit from more detailed and clearer explanation.
- It is encouraging for ACT participants and their families that the most recent NDIA quarterly report shows ratings above the national average for selected key indicators including: (most) outcomes for children aged fourteen or under, inclusion in mainstream schools, supports for young

 $\frac{https://www.ndis.gov.au/medias/documents/performance-act-31dec-17/ACT-Performance-Report-31Dec-2017.pdf}{\\$

² COAG Disability Reform Council NDIS Quarterly Performance Report: Australian Capital Territory, 31 December 2017, p. 7,

adults, and what could be described as the resilience of families. (see Appendix 1 for fuller breakdown)

- But it is concerning for ACT participants and their families that the same quarterly report shows ratings below national levels in areas such as: peer group participation, friendships, housing choices and safety, access to health services, access to post-school education, training or employment, and involvement in society more generally. (See Appendix 1 for fuller breakdown)
- It is deeply concerning that in crucial areas of social and economic participation, ACT participants according to the latest NDIS quarterly report have low and sometimes shockingly low outcomes, especially in: finding a job (16% 20%), help with choosing a home (13% 21%), developing a child's friendship circles (in various domains anywhere between 20% and under 50%). (See Appendix 1 for fuller breakdown)
- It is positive that a higher percentage (35% 36%)³ of ACT participants fully or partly self-manage their plans than the national figures of 18% to 20%.
 - o We recognize, however, that not everyone will want to self-manage all or parts of their NDIS funds. Plan-management and Agencymanagement are no less valid options than self-management. Ultimately, the critical test of the decisions participants make about their plan management preferences is that the decision arises out of their informed choices about what suits them best.
- It is positive that a slightly higher percentage (42% to 43%) of ACT plans include support coordination than the national figure of 41%.
- It is a concern that barely 5% of NDIS participants with an approved plan identify as Aboriginal or Torres Strait Islander people. The ACT figure is even

³ https://www.ndis.gov.au/medias/documents/performance-act-31dec-17/ACT-Performance-Report-31Dec-2017.pdf

lower at only 4%. We do not underestimate the challenges to increasing the participation rate of Indigenous Australians in the NDIS. But we recognize a more concerted and urgent focus is required.

- o The '10-point plan' proposed by the First Peoples Disability Network is the essential starting point for a focused discussion on what needs to be done. That does not mean the DRG agrees with everything in the plan. We simply accept it as a place to start talking. The plan can be viewed here: http://fpdn.org.au/ten-point-plan-for-the-implementation-of-the-ndis-in-aboriginal-communities
- The NDIA's Aboriginal and Torres Strait Islander Engagement
 Strategy of 2017 is welcome too. It can be viewed here:
 https://www.ndis.gov.au/Aboriginal-and-Torres-Strait-Islander-Strategy

DRG Recommendation 2

The ACT Government and the NDIA in the ACT should develop a partnership approach with ACT organisations of Indigenous Australians to develop an ACT strategy to promote greater understanding and uptake of the NDIS by Indigenous people with disability.

- o We all need to 'lift our game' when it comes to closing this gap for Australia's first peoples with disability. That's as true for us in the DRG as it is for service providers, the ACT Government and the NDIA when it comes to improving the NDIS in this area.
- We note that the ACT NDIA dashboard report shows that 10% of approved plans are for participants from a culturally and linguistically diverse (CALD) background. The corresponding national figure is 7%.
 Both these figures are too low. We need better responses and improved outcomes.

o The National Ethnic Disability
Alliance proposed a
strategy for better
engagement with people
with disability from CALD
backgrounds as long ago
as 2016. It is here

Co-design is a founding and integral concept of the NDIS ... people with disability need to be integral to every stage of the design, implementation and evaluation of the NDIS.

NEDA

http://www.neda.org.au/publications/full-statement-call-stronger-engagement-people-disability-ndis

The most recently reported plan figures clearly demonstrate that –
 yet again – this is an area we all need to do more to improve.

DRG Recommendation 3

The ACT Government and the NDIA in the ACT should develop a partnership approach with ACT organisations of culturally and linguistically diverse people to develop an ACT strategy to promote greater understanding and uptake of the NDIS by people with disability from culturally and linguistically diverse (CALD) backgrounds.

- We welcome the announcement in October 2017 that the NDIA was
 designing, testing and progressively introducing new participant and
 provider pathways. We have been interested to read the detailed Report
 on the National Disability Insurance Pathways Review (available here
 https://www.ndis.gov.au/news/pathway-review-report.html)
 - We understand and accept that trials and pilots of reforms to important operational processes within the NDIA add value. But we also believe that some changes can and should be introduced immediately.

- That the NDIA work to address identified concerns raised by participants including:
 - reduced call centre waiting times,
 - a more direct connection between participants and planners (rather than LACs),
 - greater clarity in the description of details in plan notification correspondence of what is being funded,
 - clarification of how review processes operate, speedier reviews,
 - reduce complexity of the budget to one overarching category for self-managed plans.

(See Recommendation 6)

- o We also believe the national rollout of new pathways must be accelerated because, as we report below, access and systembarriers and delays remain a problem in the ACT.
- We welcome the announcement in February 2018 that recommendations from the independent pricing review will be implemented.
- We welcome too the NDIA's commitment to providing "greater transparency and an active monitoring of pricing decisions as the market evolves and grows to adequately meet the needs of participants" 4. We hope that the NDIA Board's decision to establish a Pricing Committee will help to achieve those ends.

⁴ NDIA Media Statement on the Independent Pricing Review's recommendations, https://www.ndis.gov.au/news/ipr-report.html

• Continuing dialogue involving all interested parties is essential in this area.

The [pricing] report is a mixed bag. There are strengths, weaknesses and gaps; there are areas where further work is required.

Dr Ken Baker CEO. National Disability Services

PERFORMANCE STATISTICS FOR THE ACT FROM NDIA PUBLISHED REPORTS

NDIS participants and their families are, of course, central to any assessment of how well the NDIS supports outcomes (as its establishing legislation intends) of greater social and economic participation. We read a lot about those outcomes. And we asked NDIS participants in the ACT, family members and carers, advocates and service providers to share their experiences of the NDIS, the NDIA and the broader systemic environment of intergovernmental or interdepartmental cooperation.

In this section we report and comment on the following:

- extracts from quarterly reports of the NDIA;
- data and comments from the DRG online survey of NDIS participants;
 and
- feedback from individuals and disability organisations in the ACT.

We have separated this part of our submission into two themes:

- participant and carer perceptions of social inclusion outcomes
- the performance of the NDIA

Social Inclusion Outcomes

We drew on the most recent NDIA quarterly reports (which are broadly consistent with previous reports). The ACT performance and dashboard reports from the NDIA tell us these facts (among others). See Appendix 1 for a complete list of indicators and responses.

Results above 60%:

• 97% of parents say the NDIS helped with their child's development;

- 94% of parents say the NDIS helped them access specialist services;
- 84% of parents say the NDIS helped increase their child's communication abilities;
- 73% of parents say the NDIS helped their child fit better into the family,
 while 66% said the same about the broader community;
- 71% to 78% are happy with their home, with 68% to 83% saying they feel safe in their home;
- 72% to 77% of all carers report their health as good or better;
- 65% of carers of young adults feel in control of selecting services;
- 62% of young adults rate their health as good or better;
- 61% to 75% say they have greater choice and control in their lives;
- 61% to 79% choose what they do each day;
- 61% to 75% report no difficulties accessing health services;

Even where there are results between 60% and 75% that report a good outcome a valid question remains. What can be done to better assist the 25% to 40% who do not report positive outcomes in key areas of their lives?

There is a group of responses that are in, what we call, a middling range where confidence that better outcomes arise looks less certain.

- 59% do now or have attended mainstream classes in school;
- 55% to 77% have been helped with daily activities;
- 51% to 68% say they choose who supports them;
- 50% to 60% report improved health and wellbeing
- 46% to 50% say the NDIS has helped them meet more people;

However, the NDIA quarterly report contains some concerning figures (which in places contradict more positive rates). Only,

- 13% to 21% say the NDIS has helped them find the right home;
- 14% to 16% say they volunteer;
- 16% to 20% say the NDIS has helped them find employment;
- 17% say they participate in post-school education;

- 28% to 31% say they have a paid job;
- 23% say the NDIS has improved the knowledge and advocacy skills of participants 15 years and over;
- 26% say the NDIS has helped them with post-school learning;
- 32% of parents say the NDIS improved their child's access to education;
- 41% say the NDIS has improved support for participants over 15;
- 43% of adults aged 25 or over say they feel more in control of selecting their services;
- 43% to 47% say the NDIS has helped to improve their health;
- 45% to 49% of parents say the NDIS helped improve their child's personal relations with family, friends or in the broader community;
- 48% say the NDIS has helped them access services in the community.

We recognize that these numbers are not a statistically significant sample of an entire population out of which one could draw causal relationships. But we believe the NDIA has helpfully included such data in quarterly report after quarterly report because the data tells us something the broader community needs to understand. And some of what the data suggest is not good news.

Continuing Social Exclusion

To the DRG, the data suggests that, even with assistance from the NDIS, people with disability and their families still face barriers to participation that other people do not – or not in the same way or to the same extent.

The raw data from the NDIA quarterly report re-confirm what individuals have often said about their own lives (for example in the *Shut Out* report that contributed to building support for the NDIS). Advocates and researchers over many years have told the Australian community through reports, policy papers, consumer feedback and surveys across a broad spectrum of everyday activity that many people with disability and their families experience social exclusion. When it comes to access to schools, health

services, housing, transport, jobs, justice, social participation and community life – people with disability, including NDIS participants, have fewer options than many people with no disability.

Some of the responsibility for this continuing exclusion – perhaps most of the responsibility – sits in the wider community. Despite the very best efforts and initiatives of many individuals and organisations -- within and beyond the disability sector -- to change practices, promote more inclusive policies, commit to barrier-reduction and 'walk the talk' of social inclusion, many attitudinal barriers remain intact. Those barriers keep people out.

NDIS and the National Disability Strategy

It is also true that the NDIS is just one component of the Commonwealth Government's National Disability Strategy (although we cannot ignore it is the only component that comes with \$22 Billion attached). Nevertheless, it is not reasonable to expect the NDIS to do all the heavy-lifting when it comes to eradicating barriers to social participation by people with disability.

We need, therefore, a more clearly focused and better resourced National Disability Strategy. And people with disability and their representative organisations ought to play a more central role in implementing the NDS.

In the ACT, we recognize the commitment already made by the ACT Government to make the National Disability Strategy more meaningful through the *INVOLVE Canberra* initiative. The DRG supports Minister Rachel Stephen-Smith's commitment to reinvigorate *INVOLVE Canberra*. We urge the ACT Government to invest additional resources focused on raising awareness about the benefits of social inclusion of people with disability and

practical advances that could be made in attitudinal change and barrierreduction.

DRG Recommendation 4

The ACT Government should continue to support and develop *INVOLVE Canberra*, the ACT commitment to the National Disability Strategy. The reinvigorated strategy would benefit from even greater involvement by people with disability, family members and carers, and the broader ACT disability sector. The strategy should be adequately-funded and seek partners and champions in the ACT business community.

NDIS and Barrier-Reduction

It is no less true, however, that the NDIS can and should do more to support practical action to advance social inclusion of NDIS participants and other people with disability, through the NDIS framework known as *Information*, *Linkages and Capacity Building*.

Addressing the functional limitations that arise from a disabling condition is, of course, fundamentally important to constructing an NDIS plan. But those funded supports need to be better understood as building blocks of a plan rather than the plan per se.

NDIS plans should be more clearly and emphatically focused on developmental approaches to realizing people's goals for greater social and economic participation.

 For example: a quadriplegic woman, paralysed in all four limbs and with no finger function, will need assistance to shower, dress, and transfer into her powered wheelchair. That functional assistance and her mobility equipment are likely to be funded by the NDIS. But the funded assistance does more than simply overcome the functional limitations arising from quadriplegia. They are the bedrock of the woman achieving her personal social and economic goals. Dressed for work, leaving home in her powered-wheelchair the woman may go off into the world where her role as a teacher, lawyer or shop assistant illustrates the kind of contribution she has chosen to make to the ACT.

Currently, for a significant proportion of NDIS participants, the link between the interventions or supports that are funded to overcome functional limitations and the progressive, developmental realization of goals is absent, tenuous or not immediately clear – even to the participants themselves.

Making Information, Linkages and Capacity Building (ILC) More Effective

For people with disability who are not participants there still needs to be a clearer, stronger emphasis on how the NDIS will improve their lives. That is what the Information, Linkages and Capacity Building (ILC) is intended for.

Local Area Coordination must foster activity and outcomes that help us to reshape the mainstream in more inclusive ways. There is a risk, however, that the distinction between LACs and planners is being blurred unhelpfully.

The role of LACs in the ACT must be more clearly defined. ACT participants express lack of clarity about the relationship between a LAC and their planner. There is a resource allocation risk that work by LACs intended to contribute to re-shaping

Didn't know about LACs at all and still don't understand what they do or how they help. Do I need to contact them for help or [go] to NDIA??

A participant

the mainstream will always come second to 'getting people in' and managing plans.

NDIS Plans and Increased Participation Outcomes

When it comes to changes the NDIS could make to facilitate better social and economic outcomes for participants, we particularly urge renewed NDIA action in these policy areas:

- More plans need to activate more support for employment-related goals.
 NDIA planners need to take a more proactive position on encouraging participants to consider work-related measures. Employment accounts for only 2.5% of the total annualized committed support nationally of the most recently approved plans according to the NDIA quarterly report.
 - o At 1.6%, the corresponding figure for the ACT is unacceptably low and shockingly inexplicable. What possible reason could explain why ACT plans contain barely 60% of the dollar value of the already too low national benchmark?
- The processes and decision-making framework behind Supported
 Disability Accommodation (SDA) and Supported Independent Living (SIL)
 can be opaque and mysterious to NDIS participants and providers alike.

 The relationships between support (the SIL component), the bricks and
 mortar (the SDA component) and other NDIS plan supports typically
 outside the home is not always clear.
- We understand that expanding the supply of affordable housing for people with disability through an evolving and expanding market mechanism is a long-term challenge.

The NDIS is not the only player. But the estimated \$700 million annually that constitutes the NDIS fund for housing is, in our view, still weighed down too heavily by the historic practices of the former block-funded disability accommodation arrangements. More needs to be done – and done more quickly – to release the potential for reform so that the \$700 million can be the catalyst for change we need.

The recently-published paper by The Summer Foundation should be read by everyone with an interest in this 'wicked problem' (see it here: https://www.summerfoundation.org.au/resources/ndis-specialist-disability-accommodation-pathway-to-a-mature-market)

- It is a fact that most of the houses that most Australians now living will ever occupy have already been built. Home Modifications will always be an important part of supporting NDIS participants to live in their homes as valued members of communities to which they already belong. This will become increasingly important as a growing number of people who entered the NDIS aged under 65 choose to remain NDIS participants as they 'age in place'. Home modifications need to be easier to access, quicker to approve and completed in a timelier manner.
- School transport problems -- from availability, cost and the lack of clarity about who funds what -- need to be eradicated.
- More attention needs to be given to the tension between the closelyrelated disability and health systems. The differences between health matters and a disabling condition can be difficult to discern. But there is a distinction between the two. We do not wish to return to or carry-on the cost-shifting debates of the past.

DRG Recommendation 5

The ACT Government and the NDIA should act urgently together to identify and eradicate unintentional and restrictive interface barriers between different mainstream support services and the NDIS. The two tiers of government should draw on the information, examples and solutions proposed in this and other submissions to the inquiry.

We make more comments about interface and boundary issues between the NDIS, and other service systems (ACT and Commonwealth) later in this submission. See pages 41 to 49.

PARTICIPANT FEEDBACK ABOUT ENGAGING WITH THE NDIA

We support the NDIS. We believe that this new system for supporting people with disability is much better than the former, under-funded system. We acknowledge that more people are being supported by the NDIS than ever before – in the ACT almost twice as many people as before.

We repeat those observations because some of what follows – drawn as it is from participant feedback – is critical of NDIA operational settings and processes. As we said before, one can be a supporter of the NDIS and suggest ways in which its services can be improved.

We acknowledge too that the NDIA has accepted the need to change and improve both the participant and provider pathways. Those commitments are welcome. Change was and is necessary.

We believe that change needs to come quickly and that some, straightforward or rudimentary improvements can be instigated without waiting for the conclusion of current trials into new pathway.

What the NDIA Tells Us About Participant Satisfaction

Proportion of participants describing satisfaction with the Agency planning process as good or very good – most recent reports by quarter (ACT)

Indicator	National	ACT	Difference
2015 – 2016 quarter 1	93	100	+7
2015 – 2016 quarter 2	100	94	-6
2015 – 2016 quarter 3	100	100	0
2015 – 2016 quarter 4	95	93	-2
2016 – 2017 quarter 1	85	92	+7
2016 – 2017 quarter 2	84	79	-5

2016 – 2017 quarter 3	88	81	-7
2016 – 2017 quarter 4	84	N/A	N/A
2017 – 2018 quarter 1	84	N/A	N/A
2017 – 2018 quarter 2	83	N/A	N/A

The NDIA satisfaction survey has always been at high levels that most organisations would be pleased to achieve. We do not doubt that many NDIS participants are satisfied or very satisfied with the scheme, the outcomes of having a plan, and the engagement with the NDIA. But it is true – in the DRG survey attached as Appendix 1, in other externally-organised surveys by non-government organisations, and in the knowledge we have gained through our disability networks – that many people (participants, carers and service providers) also express high levels of dissatisfaction about engaging with the NDIS. We believe the NDIA should quickly introduce a different quality surveying mechanism that is both transparent and persuasive.

It may surprise no one, however, that as the scheme moved from trial to full scheme transition there appears to have been a significant dip in satisfaction ratings. As we approach the 'new normal; of full scheme there is a risk we could be at the start of a downward trend. This is a risk the NDIA, itself, implicitly acknowledges:

"Participant satisfaction continues to be high, but has dropped during transition, compared with trial site experience."

We acknowledge too the comments made by the NDIA about quality assurance when it released the December 2017 Quarterly Report. The Agency wrote:

"While the December quarter's rating is consistent with the experience since the start of Transition, the NDIA acknowledges the need to

continually improve and continues work to significantly enhance the experience that participants and providers have with the NDIS." 5

We welcome that commitment. Nevertheless, we think that in the light of the satisfaction 'dip' and the continuing rapid expansion to full scheme, it may be the right time for the NDIA to revisit its satisfaction surveying framework. There will soon be quarter of a million of participants in the NDIS. A satisfaction rating framework and methodology that fitted the trial phase may need to be re-fashioned for the years ahead.

As the DRG in the ACT we are particularly focused on the NDIA figures available for the ACT. They suggest the decline in satisfaction levels may be more pronounced. We need to know why that might be.

It could be explained – in part – by comments we report below from ACT participants. We think it may also have something to do with the loss of an ACT-located senior regional management position with the NDIA.

ACT participant feedback to the DRG

We asked people to share their experiences of the NDIA. We used an online survey (complete report at Appendix 2). We had a Facebook forum, conducted telephone interviews and visited participants at home. We attended NDIS-forums hosted by other organisations as part of their engagement with the ACT Legislative Assembly inquiry into the implementation and performance of the NDIS in the ACT. We read a lot of ACT-based documents about the NDIS submitted to earlier inquiries.

We recognized earlier that the NDIA quarterly report's survey responses are not statistically significant research findings, and the methodology of

⁵ NDIA Media Release on 31 December 2017 Quarterly Report, https://www.ndis.gov.au/news/media/quarterly-report-q2-2017

collecting data during planning meetings may inhibit criticisms. Neither – we make clear – are the DRG survey findings scientific proofs. Nevertheless, we believe both the NDIA statistics and the DRG numbers, tell us something of interest.

They make valid observations (even if we raise a skeptical eyebrow). It's unlikely, for example, that nationally and in the ACT 100% of participants were satisfied with the NDIS in the 3rd quarter of 2015-2016. And when the DRG survey closed on 23 March 2018 – it was probably not credible to extrapolate from our pie chart to claim that 62% of all ACT participants are "not at all satisfied by their engagement with the NDIS".

The truth sits somewhere in between. The NDIS is highly-valued but its operational interface is not problem-free for both participants or providers.

The DRG is of the view there are improvements to be made to NDIA processes. We should listen to what NDIS participants, carers, providers and advocates tell us. Then work together to fix the problems.

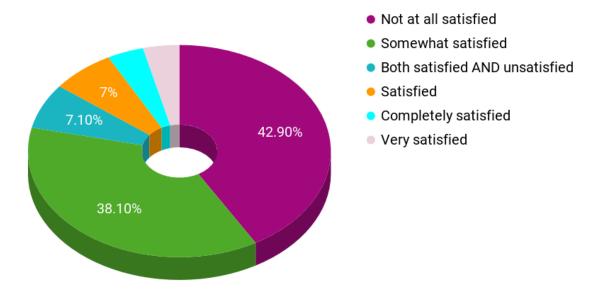
Some of what survey participants told us is reproduced in the pages that follow. The complete survey results (unedited) appear in Appendix 2.

A participant told us she has a new wheelchair which she still cannot use because the home modifications haven't been approved so she cannot get safely in and out of her home.

A carer told us that the participant was losing instead of gaining independence skills because the support worker was doing for them rather than with them.

Another participant told us that the NDIA was listening to his mother rather than to him.

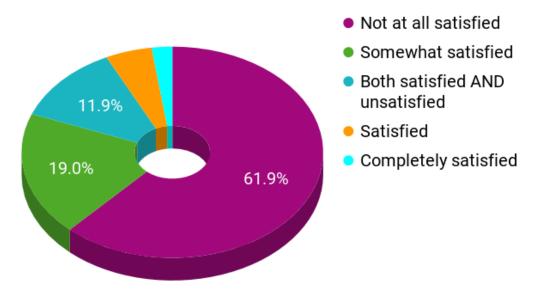
How would you rate your experience ACCESSING INFORMATION about the NDIS?



<u>Selected comments</u>

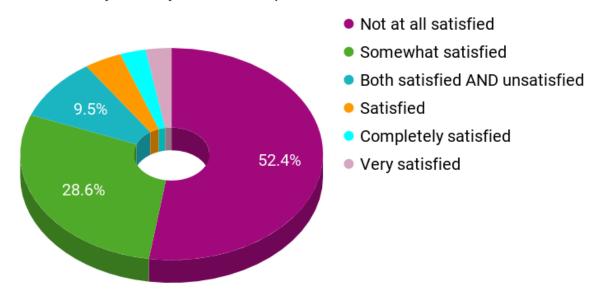
- "access OK"
- "It is up to the individual to go find what they need."
- "accessing information is like trying to get blood out of a stone."
- "I was very unsatisfied until our most recent review in December 2017 when I finally got an LAC with the ability to help me understand what I needed to know ..."
- "I have a son in the scheme and I feel I only have information as I work in the sector ... the information is forever changing, and it becomes frustrating that most of it is word and mouth"
- "Information on the NDIS website is extremely high level and brief and lacks the comprehensive details required to navigate the NDIS guidelines. NDIA staff are regularly unable to answer questions and lack the knowledge you would expect from staff working within the organisation. Documentation provided by the NDIA regularly misses the mark, is difficult to follow or just plain wrong."
- "It's hard to get simple information i.e. some 'get' things others don't"
- "The last 12 months have been very stressful. Changing laws without communicating them to the community disadvantages us."

How would you rate your experience ENGAGING WITH the NDIS?



- "Had to make regular phone calls i.e. weekly or fortnightly to push the NDIA to review and authorise a support that was included in my first plan - I am now onto my third plan and received the outstanding support 3 weeks ago, after advocacy from a NGO and my family carer."
- "Both fantastic and terrible experiences."
- "Very slow to respond. Very inconsistent information. Some staff have been very good, empathetic. Other staff have been absolutely rude. I am always left with questions after each interaction due to staff not having the answers or not getting back to me."
- "They have NEVER answered an email. They rarely answer the phone. They say they are looking into fixing something for you, and you never hear from them again! ..."
- "Wait time to get put through on phone is unbearable."
- "The last 12 months have been stressful. They have [tried] to fix some things up to their credit, but some things are still outstanding e.g. system portal issues and inconsistent decisions for services in my son's case in house support."
- "central phone line can never help and have to forward to local area who often and usually do not respond."

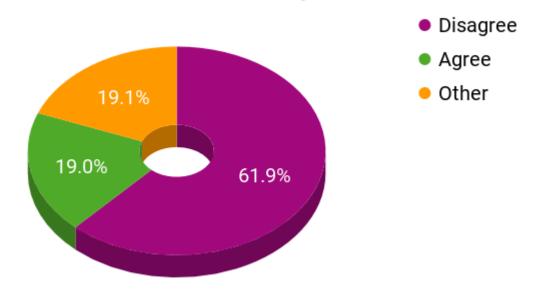
How would you rate your overall experience of the PLANNING PROCESS?



- "Only the first year in 2015 was satisfactory. Since then the process has
 deteriorated. It has reached the absurd point where my LAC in 2017/18
 will not give me a copy of what she submitted on my behalf ... She told
 me the information belongs to the NDIA"
- "The first planning experience was fantastic. We had someone out to our house every week for two hours for four weeks until we had the plan right. The next plan was conducted face to face in the NDIS office and worked well as information was taken from the first plan and new items included. The third plan was also conducted at a face to face meeting and even though we provided plenty of evidence and outlined that things had not changed much but had in fact gotten worse with a new mental health diagnosis from a psychiatrist. None of the new factors were taken into consideration and the plan provided was less than in the 2nd year. We instantly requested a plan review which took up to 4 months (with a lot of chasing from us). The review was conducted over the phone and took several different phone-calls over several weeks. The updated new plan reflected the changes we had originally discussed in the face to face meeting. I think a couple of the biggest problems are that, one, the participants don't get to see the draft plan before it is approved (which was the case in the beginning in the first plan) and secondly that the planners don't have enough knowledge about different mental health needs in people with a disability "

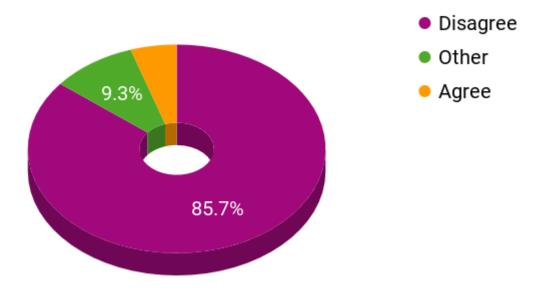
- "Planning for my son has been done by me, no input from NDIS at all."
- "planners don't have breadth of experience which is fine but then they shouldn't determine our lives by just handing us a plan. Our planners have given good funding for their area of experience but often is not what we need. Assistive technology is a major problem"
- "On the first planning meeting (with NDIS planner), was made to feel absolutely defensive about seeking out reasonable therapies. Second planning meeting (With LAC) more positive interaction, but also realising they are not making any decisions, they are simply gathering information."
- "From our experience there is no correlation between supports requested and quoted for by professionals (medical practitioners and therapists) that are also backed by clinical reports and evidence to the supports actually included in the plan."
- "Generally, the outcome has been reasonable, although they are very poor at knowing how to do it, but when I arrived for the 2 planning sessions I've had they've had no one ready to do my planning. First session someone eventually found then the room booking ran out so planning cut short, second session waited almost an hour for the review (that they booked!) before someone took pity and then did a poor job."
- "It was very rushed."
- "As of our third plan which commenced January 2018 I am satisfied.
 Prior to that, for two years, I was very unhappy and felt helpless to
 understand what the funding could be used for and how best to use it
 to advantage my child. I was frustrated and felt helpless. I gave up
 trying. It was too hard."
- "Our son has had 3 plans and the approach has been different each time. Why??"
- "Our third planning review was June 2017. Disaster. By Aug / Sep a review saw NDIS apologising for their oversights and as mentioned above inconsistent decisions for inhouse help and portal payments still in process of trying to sort it out. I work full time and it takes a lot of time to follow up."

I found information about the NDIS easy to understand



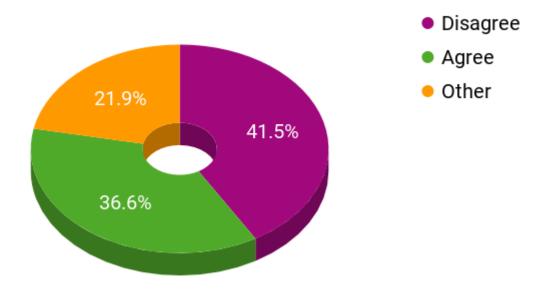
- "Some information is easy to understand. Some is not. Some information is not accurately provided by NDIA staff."
- "complex."
- "My Mum is fine to understand information produced by the NDIS on my behalf, but she observes that some of the NDIS communications to be quite ill-considered."
- "too many changes to keep up"
- "Some information is easy to understand while others is hard to find and can be very frustrating when you have to call the NDIS office and sit on hold for extend periods and then the person you talk to can't answer your question."
- "Overwhelming, frustrating, intimidating, not user friendly at all."
- "there is very little useful information available."
- "I strongly believe the information provided by the NDIA is deliberately evasive."

I have had timely responses from the NDIA to my inquiries



- "I have had timely responses from the NDIA to my inquiries."
- "Very delayed or no responses for a long time, but prompt attention after a formal complaint was made."
- "Getting worse."
- "They never call or email back even when they say they will to organise a plan review. Then when you ring to try and organise it they NEVER call back. Disgusting for a Public Service Department."
- "what responses?"

Because of the NDIS, I feel more optimistic for the future



- "Yes, in terms of at least being able to access some essential supports. I
 can't feel completely optimistic as there is always the possibility that
 your funding is cut, and essential therapies may not be able to
 continue."
- "She will never feel optimistic she worries what will happen when she is unable to care for my nephew."
- "Cautiously optimistic wold be a better description."
- "Strongly disagree. As I mentioned before there is much suffering in our lives, now that we live with the constant threat of having our supports taken away."
- "I am glad the government supports vulnerable people otherwise life would be impossible. However, I feel the same about the future. I have asked for one recreational item for my son through the NDIS and it was declined. apparently disabled children are not supported by NDIS to be included in sport and recreation."
- "Overwhelming, frustrating, intimidating, not user friendly at all."
- "Based on events of late, I'm not sure"

We asked survey respondents to tell us up to three things about the NDIS they value, based on their experiences. Here is what we were told.

ON THE UP SIDE OF VALUE & THE NDIS

- Greater control to choose different providers;
- the potential to move out of the current living arrangements
- in short, the potential of the NDIS is valuable to us.
- Improved my self-esteem, access to supports and to allied health services e.g. psychologist and physiotherapist that have made a big difference to wellbeing
- The financial support.
- The support received is much more appropriate for my needs.
- The choice of support is very valuable.
- I am glad that my family no longer has to bear as much personal or financial pressure to support me with my disability.
- participant now has sufficient funding for required 24/7 accommodation support and

- ability to enter the community from time to time
- The potential for financial support.
- Finally finding staff who will help with an enquirer rather than telling me I'll just have to wait.
- Being able to access support so parents can retain full time working.
- Receiving respite that is suited to the participant
- Participant being able to get out into the community without it always being up to the family.
- Choice,
- avoiding services,
- assisting our son to take up valued roles in the community
- Self-managing the funding in my son's plan so we can purchase the right services that are for him.

- Having access to a support coordinator when it was available was invaluable in navigating the NDIS planning process.
- More choice re domestic assistance.
- Participant centricity
- The freedom that comes from not dealing with the previous government support and system
- Support for our child, ourselves and family unit.
- Access to allied health services.
- Being able to have autonomy over what supports and therapy our child can have under Choice and Control.
- 1st ever support for my daughter.
- Some ability to access community without a parent and try to improve independence
- More therapy available
- Plan can be NDIS managed
- Accessing funding for personal care and "in kind" support for school.

- Access to funding for home modification that has allowed personal care for the future be possible
- Help to fund therapeutic interventions that allow us to continue to develop function
- Access to acupuncture
- Daily assistance (until funds run out)
- I get funding,
- I can self-manage,
- Portal makes claiming easy
- I love my support worker. She is amazing.
- So thankful to receive a mobility scooter.
- Seeing my psychologist regularly is so helpful.
- Now we have aspirations for the future.
- Now we have opportunities we did not previously enjoy.
- Now we feel respected and validated.
- it's available
- Helps us work and get my son an education
- Provides respite.

ON THE DOWN SIDE OF VALUE & THE NDIS

- Nothing has been of value
- everything has been disappointing
- Nothing
- The NDIS ensures my life is very busy filling in forms, making appeals, etc.
- The NDIS helps me focus my anger
- The battle with the NDIS gives me strong reasons to get out of bed each day.
- I'm getting experience dealing with an intractable bureaucracy
- There is plenty of scope for improvement

- There is enormous potential for a better future
- There are none.
- Nothing
- None
- Frustration
- Complexities
- Unreliable in making their payments.
- Loaded question! It's been
 difficult as a new user of formal
 supports to get what I need, but
 I have accessed some of the
 equipment I badly needed so
 that's a start

SUMMING UP WHAT PEOPLE SAID THEY WANT

The people who completed the DRG survey gave clear indications of the changes people want for their engagement with the NDIA at all stages of their engagement and / or pathway journey. ACT peak disability and carer non-government organisations have also surveyed their own networks to present information to the Legislative Assembly inquiry. We believe that their survey results are broadly the same as those in the DRG survey. Similar messages also come to the fore whether we speak with participants, family members and carers, advocates or service providers.

We acknowledge that work is already underway to develop new pathways for participants and providers. We know they will be progressively rolled out across Australia in the period ahead. We know too that some changes are being implemented without waiting for trials or pilots to be completed. That is welcome news. We acknowledge that improvements are underway.

Nevertheless, the points below give a concise summary of what seems to us are the almost-universally preferred results people we engaged with want.

- Clearer, simpler, more accessible information at all stages of the NDIS journey.
- A more intuitive and user-friendly NDIS web site, and portals.
- And end to inexplicable and unreasonable delays from first point of contact with the national call centre, to all parts of the processes of developing plans, reviewing plans, and engaging generally with the NDIA.
- A direct connection between the NDIS participant or nominee and her or his planner, including contact information such as the planner's NDIA email address and telephone number.
- To view the final draft of the plan submitted in the participant's name before it is formally lodged.

 To receive clearer and more detailed information in plan notification letters and on the participant portal about how the amounts allocated in a plan have been calculated and what assumptions have been made about hours of support and/or service types to be funded.

DRG Recommendation 6

The NDIA be more responsive to user needs, in relation to participant feedback on access, information, waiting times, transparency of decisions and plan design and delivery.

Answer the phone in a timely manner

A participant

The Braddon office could reactivate their email address and there could be a direct phone contact ability.

A participant

More information could be provided to Carers like myself by regular informational emails about changes or who to contact for various packages or information on what the LACs do or can assist with.

A carer

More timely response to assessment / approval of the renewal of a plan.

A participant

Additional advocacy funding and also some case workers.

A participant

Listen to the parents!

A parent

Consistency!!!!

A participant

TOWARDS A SEAMLESS SUPPORT ENVIRONMENT & SUSTAINABLE SERVICES FOR THE NDIS IN THE ACT

We wrote earlier in this submission that the National Disability Insurance Scheme is not the only component or player in securing better outcomes for people with disability and their families. It is part of a broader approach known as the National Disability Strategy.

Mainstream Interface & Boundaries

Beyond the National Disability Strategy sits what are often called mainstream services such as education, employment, health, housing, justice, transport, etc. People with disability – whether they are NDIS participants or not – rely on mainstream supports in more or less the same way as everyone else.

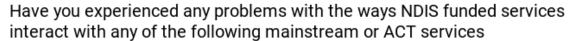
- We all benefit from a good school teacher who sees our potential.
- Most Australians of working age have a job.
- If you need a tooth extracted, you need a tooth extracted.
- We all want to live in a comfortable and safe home.
- The rule of law applies to everyone.
- We all need to get from A to B (which in the ACT probably means you'll pass through the Woden bus interchange at some point of your life!)

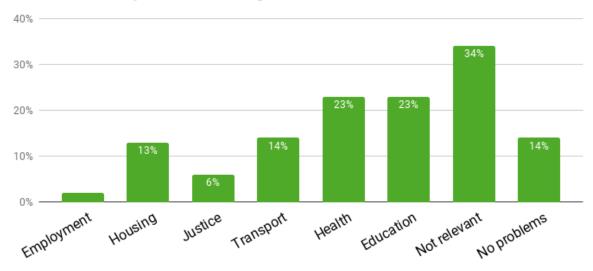
NDIS participants have a right to access these services on no less favourable terms than any other Canberran. That requires mainstream services to develop and implement inclusion policies and practices that may require reasonable adjustments to existing arrangements.

The relationships between supports funded by the NDIS and mainstream services are, therefore, critically important. At the point of need or service delivery – dentistry, open heart surgery, a child's end of year examination in

Mandarin, when a judge calls upon you to testify, or when the bus arrives at the Woden interchange – it is essential there should be in operation the seamless link or interface between the mainstream service someone needs, and the supports funded in a plan, if you're an NDIS participant.

In the DRG survey (see Appendix 2 for full results) we asked people to tell us which mainstream services – if any – they had experienced problems with. Here's what we were told.





The headlines?

- 14% said no problems.
- 34% said it wasn't a relevant question for them.
- 52% -- more than half said they'd had a problem with one service or another. The arithmetic of the responses above tells us some people indicated they'd had a problem with more than one service.

It's our view that interagency and intergovernmental frameworks, planning, partnerships and operational relationships need to be working if the seamless interface we require is to made real in the lives of people with disability whether they be NDIS participants or not.

- Different service systems Commonwealth, ACT Government, nongovernment – need to understand each other, talk broadly the same language, and agree as a matter of standard operating procedure to work together to provide seamless support across intergovernmental, interdepartmental or cross-sectoral boundaries. That's not always easy but it is essential.
- All service systems need to put the client / customer / participant at the centre of everything they do with or for them.
- A vibrant and sustainable service system needs to exist.

We shall make brief comments, therefore, on aspects of the mainstream / NDIS interface in the ACT, and the sustainability of the service systems in the ACT (primarily the non-government sector). These observations below add to comments already made in Section 4.

Who is responsible for what?

At the heart of the difficulties surrounding interface issues is a comparatively straightforward question (although we acknowledge that there can be complexities in finding an answer that works for everyone). It is:

In any given situation, who is responsible for what?

For the DRG it is important that taxpayer funded service systems operate from a common values base. That involves all services systems recognise and welcome the fact that everyone, regardless of their disability "level" or "type", is part of the ACT community.

We are not being naïve here. We are not trying to make disability invisible or pretend difference doesn't exist. We are suggesting that – because difference exists – mainstream systems need to accept that one-size solutions do not fit all.

Here are some 'worked examples' of 'wicked problems' or thorny questions:

Education

A recurring problem is partly about the funding assumptions in people's
plans that are not made explicit or explained. These supports are not
clearly visible to all stakeholders and lack of transparency creates
confusion about what is education's responsibility and what is a
disability matter.

The answer is clear, for instance, when talking about who pays for a child that needs peg-feeding at lunch time to make sure they eat. But it's less clear for less intense supports such as for toileting or behaviour support at school.

Similarly, some families are very clear that support for homework / tutoring for a child with disability is not the same as for other children. The additional intervention need arises from a disabling condition which families see as a valid NDIS-funded support. The NDIS does not always agree.

o Solution?

Don't include assumed supports in NDIS plans or, if they must be referenced, be specific, transparent and much clearer.

Employment

- People with disability including NDIS participants are heavily and disproportionately under-represented in the work force.
 - o Solution?
 - Increase the focus on employment in pre-planning discussions.

- Increase the focus on employment-related outcomes in more NDIS plans.
- Increase the share of NDIS funds within NDIS plans going to employment goals and outcomes.
- Mindful of the imminent de-regulation of the market for
 Disability Employment Services strive to ensure that all
 Commonwealth funded employment programs align with
 NDIS guidelines. (The disconnection in this policy and
 program areas poses particular problems for the ACT
 provider LEAD)
- Develop Disability Inclusion Action Plans in mainstream organisations so that when a well-funded and highlymotivated NDIS-supported job-seeker comes your way she meets a receptive potential employer.

Health

 Who pays for which supports – a classic (if regrettable) example from the past centred on showers: was the support needed because of a health condition or a functional limitation arising from a disability.

So, when does a health condition, or a collection of health conditions, constitute a disability and when are they clearly health conditions? Recent decisions in Administrative Appeals Tribunal around funding for a child with epilepsy imply the NDIA may have taken an overly-proscriptive definitional view in this area. Overall, however, this is an interface / boundary area that lacks clarity.

o Solution?

The NDIA should be more open to recognising that health conditions can and do cause impairments which create functional limitations that necessitate specific disability supports.

And Health should resist any temptation to shift costs through carefully worded diagnostic descriptions.

Housing

o A person with disability may need social housing. Their NDIA funding would cover their Supported Independent Living (SIL) costs. They also must be on the ACT housing priority housing list to be allocated social housing. These two requirements can become a chicken and egg situation. NDIA says we won't fund you until you have a house; housing says we won't give you a house until you have funds for support.

o Solution?

- Greater transparency, communication and cooperation between housing authorities and the NDIA about timing and the tensions between different policies and frameworks in the short term.
- Further policy work and joint-planning that sorts out how social housing for disability is handled and who is responsible for what.

Early Childhood Intervention and the NDIS.

This is an area of interface and directly-funded support that has been raised with the DRG by a small but passionately interested range of respondents; parents of children with disability. We made some observations in the earlier section discussing NDIS implementation and quarterly report survey data.

From the comments we received, we highlight these observations. (See also relevant comments in Appendix 2 relating to interface issues and children).

 The interface between the NDIA-funded supports and education needs consistent, ongoing attention but there are difficulties in some instances of ineffective relationships between providers who can't or will not liaise directly with schools.

- Therapists and education need to work in ways that complement each other's roles.
- Families often have to be their own service coordinators during the early years of development of a child with disability – with or without a
 - diagnosis. Parents can
 experience knowledge gaps
 because they may not know
 what they need to know during
 the crucial early period.
- The knowledge base of professionals and the NDIS can be low, which can result in a restrictive over-emphasis on citing a diagnosis rather than looking at functional impact.
- Transition points are highly stressful.

Parents of children with disability need to be tireless, resourceful, insistent, nimble and vigilant simply to ensure their children receive the support they need. Many parents have to multi-task and juggle.

A parent

Psychosocial disability supports

We understand the tensions that exist between people with psychosocial disability and the emerging cross-sectoral support networks for NDIS participants. We encourage all stakeholders in the development of this comparatively new exciting framework to place the participants needs front and centre at all times.

 13% (a little fewer than 800) ACT participants have a psychosocial disability (compared with 7% nationally)

- Numerically, therefore, people with a psychosocial disability are the ACT's third-largest diagnostic group.
- 14% of the annualised committed support (\$\$) for active participants is allocated to plans for people with psychosocial disability (compared to 6% nationally).

The ACT clearly has a larger proportion of participants with a psychosocial disability than Australia as a whole. ACT plans contain more than twice the proportion of funds allocated to plans nationally for psychosocial disability. We think this is a comparatively good outcome. It is roughly consistent with (slightly above) what we should expect for the national scheme at full roll out.

The higher rates of participation in the ACT may be because during transition both ACT Health and the NDIS Taskforce ensured that this group were a priority. This too is a good thing. But it may also indicate an additional upward pressure on numbers and support costs within the estimates for full scheme across the whole NDIS.

A focused and intense commitment in the ACT has resulted in the number of eligible NDIS participants with psychosocial disability exceeding estimates. We want all eligible people to be in the scheme. We cannot, however, escape the implication of those two observations. Success in bringing everyone into the NDIS who is eligible for support (the preferred and required outcome) potentially places pressure on the NDIS total budget if actual numbers are greater than those estimated. And we have seen in the recent quarterly report that actual numbers current sit at 129% of the first bilateral estimate.

We note that in its first submission (July 2017) to the Productivity Commission inquiry into NDIS costs, the Mental Health Community Coalition ACT wrote:

The experience from the ACT NDIS trial was that allocating planners with mental health knowledge and experience to planning processes with people with psychosocial disability and the availability of pre-

planning support to individuals, were two key aspects of achieving more consistent and appropriate plans for people with psychosocial disability. After the transition to full-scheme roll-out, these aspects are no longer in place and outcomes for people with psychosocial disability have deteriorated.

The DRG hopes the reported deterioration has been reversed. We fear it may not have been.

In the same submission MHCC reported concerns about loss of support arising from interface and boundary issues between the NDIS, ACT mental health services, and housing support (in particular). The MHCC wrote at the time,

It is also the experience in the ACT that the interface between NDIS and mainstream health services, including tertiary mental health services, remains poorly defined and poorly understood. This leads to attempts at cost-shifting and refusals on either side to take responsibility for providing critical supports to NDIS participants.

We would be troubled to learn that no remedial action has been taken since last July to rectify those problems.

Disability Inclusion Action Plans

ACT Government departments and agencies would be better suited to building and sustaining their side of the seamless interface with other agencies and tiers of government if they adopted a more coherent and strategic approach to promoting access and inclusion for people with disability to their own services, and workforce. The DRG believes all ACT Government agencies should be required to develop, implement and periodically review Disability Inclusion Action Plans.

DRG Recommendation 7

The ACT Government should require all government departments to develop and review regularly Disability Inclusion Action Plans. The first iteration of approved plans should be in place by 30 June 2019.

Structural and operational matters

The ACT Office for Disability

The ACT Government was correct to establish an Office for Disability within the Community Services Directorate. The Office is critically important in at least two areas (among other important roles it fulfils):

- As a strategic driver of disability inclusion practices across the whole of the ACT Government;
- As the critical policy and operational link between the ACT and NDIS
 regarding NDIS implementation in the ACT and encouraging /
 supporting the development and maintenance of seamless interface
 activity with mainstream services.
- The ACT Government is also to be commended for the considered approach which it took to the transition to NDIA for services and supports in the ACT. The government recognised that some supports would continue to need to be funded outside of the NDIA, particularly for people who do not qualify for NDIS participation but also for those services which are not appropriately funded by the scheme. The retention of funding to specific disability services such as
 - o disability assessments including:
 - assessments of developmental delays in children, assessments of Autism Spectrum Disorder, functional impact assessments to help establish disability impact and support needs;
 - disability advocacy services;
 - and the retention of the Community Assistance and
 Support Program (CASP) within the Department of Health

is an important recognition that the ACT retains some responsibility to meet the needs of people with disability in our community.

DRG Recommendation 8

The ACT Government should continue to support and adequately resource the Office for Disability as a strategically important entity with government, in relations with the NDIA and across the wider Canberra community.

The NDIA in the ACT

The NDIA needs a physical presence and high-quality team of dedicated staff working from premises in the ACT. In our experience – from our different perspectives – NDIA personnel are dedicated and deeply-invested in delivering the best outcomes possible for NDIS participants in the ACT.

We believe the NDIA decision to relocate senior management responsibility for NDIA activity and relationships in the ACT to New South Wales was a mistake. There can be no doubt that relationships suffered and the effectiveness of the intergovernmental partnership between the NDIA, the ACT Government and other Commonwealth entities was diminished.

These observations have nothing to do with geography, distance or even demographics and population distribution in this region of Australia. It is about democratic and jurisdictional context.

The ACT is a full partner in the joint-venture enterprise that is the National Disability Insurance Scheme. With its own Legislative Assembly, law-making powers and role in the structures of the Commonwealth of Australia it is more than simply another regional area in another State or Territory (important as regional areas are to those who live, work in and serve them).

ACT Ministers sit as members of COAG, the Disability Reform Council, and senior public servants in ACT Government departments are members of the many senior officer groups that inform the operational framework within

which the NDIA Board makes its independent decisions and NDIA senior executives take operational decisions.

The NDIA in the ACT should be led by a more senior NDIA officer. This implies no reflection on the calibre of current NDIA staff members in the ACT. It is a recognition of the realities of NDIA obligations and operational imperatives in a federated Commonwealth.

The Disability Service System in the ACT

We have made comments above about the NDIS, the NDIA, and Federal and ACT Government mainstream services. We now add brief comments about the service sector, primarily focusing on non-government interventions.

The NDIA quarterly report to 31 December shows the following:

- 1,071 registered providers of all types in / for the ACT
 - o We should note that very many of these providers are based out of the ACT but may supply goods, services or products to ACT participants. For example, there are not 30 vehicle modification providers in the ACT, although that number is given in the quarterly report.
- 254 (24%) are sole traders (as distinct from 42% nationally).
- 817 (76%) are organisations (as distinct from 58% nationally).
- 80% to 90% of payments made by the NDIA are received by 25% of providers.
- 39% of ACT registered providers had shown no evidence of activity prior to 31 December 2017 (as distinct from 49% nationally).
- There are 1.14 providers per participant in the ACT (as distinct from 1.54 nationally).

It may be folly to attempt to characterize the supply side of the ACT market from a small set of statistics, but we can discern certain features. Reflecting the location of Canberra, we can see that the supplier base is compact and more isolated than any other capital city (excepting Darwin and Hobart). There is a higher proportion of organisations providing services than the national picture. A smaller proportion of service providers are inactive, which one sees as good; not least because there are fewer providers per participant than reported nationally.

The ACT could not be characterized as a 'thin market' in NDIS terms – particularly in contrast to remote and very remote regions of Outback Australia. But the city's location, population and the internal dynamics of the ACT economy (with disproportionately high levels of highly-educated, white collar, public sector jobs – Federal and ACT governments, two universities, TAFE, and defense industry) present challenges for the further development and maintenance of a disability sector workforce with the skills and values required as the NDIS matures.

ACT participants are well-served by dedicated and supportive providers. We have a bigger provider base and more choice over which to exercise control in a developing and maturing market than other regional towns or cities. But there are constraints which may curtail participant choice, particularly regarding niche or specialist (predominantly therapy) supports.

The Disability Sector Workforce in the ACT

We are aware of the considerable body of research and work by National Disability Services (NDS) on national and ACT workforce metrics and development challenges. We commend its submission to the inquiry.

 We know the sector's workforce is about 70% women. We contrast that with the NDIA quarterly report data which shows 60% of ACT participants are men. We're not entirely sure what, if any, significance that imbalance may have. But it's interesting and raises at least a couple of questions:

- Can more be done to encourage men to consider the disability sector as a career option?
- o Given that women constitute 50.04% of Australia's population are we sure the NDIS is reaching all eligible women with disability?
 - It may be that gender statistics around life-expectancy explain the proportions of men and women in the ACT NDIS statistics. But we don't know the reason. It is data the ACT Government, working in conjunction with the NDIA should examine to ensure no unintentional gender bias is distorting take up of the scheme.
- Sustaining an NDIS-ready workforce is genuinely challenging given what NDS reports about the ratio of permanent (falling) to casual (rising) and part-time (also rising) employment in the Australian Disability Workforce Report. The face of work is shifting in most sectors of the economy in every OECD country. We need a better understanding of what must be done to secure the workforce for the years and decades ahead.
- Given what we call the "internal dynamics" of the ACT jobs market, and what we know are the diverse requirements of the disability sector

 – support workers, allied health professionals, psychosocial disability

 specialists, etc., -- what more can be done to grow the disability sector

 workforce?

Human Services Register

The DRG does not possess the detailed operation knowledge of the register to offer precise or forensic comments. We do believe, nevertheless, that

maintaining a robust and effective framework for ensuring the quality and integrity of support services for people with disability is vitally important. We note, in that regard, both the calls for and establishment in some jurisdictions of inquiries into historic and current abuse of vulnerable people with disability.

We do note the comments by some stakeholders that the relationship between the NDIS and the Human Services Register should be more transparent, while remaining consistent with any individual's legitimate right to privacy.

We raise one further aspect of the NDIS / HSR interface that arises from earlier references to the implementation of the NDIS in the ACT. We welcomed the substantially higher proportion of fully or partly self-managed NDIS plans in the ACT (35% - 36% compared to 18% to 20% nationally).

Participants who self-manage or plan-manage their NDIS supports have greater flexibility and choice over who may be paid for those services. It is not required that their providers be NDIS-registered. No one knows the precise extent to which ACT participants make use of non-registered providers. But many do. The Human Services Register would not come into play in those situations or relationships.

Local Area Coordination

We have made comments on the LAC role at various points throughout this submission. A few brief additional observations are worth making.

- In the first jurisdiction to reach full scheme, Local Area Coordination was a late addition to the ACT framework.
- As we have already stated, the recent opening of a fully-staffed Feros
 Care office in Philip is a positive development.

- There is a fundamental difference between local area coordination and support coordination in individual NDIS plans. We must not lose the latter because local area coordination – no matter how good – is not a substitute.
- ACT LACs have an important role to play in helping mainstream services and the wider community to engage with a disability reform agenda for greater social and economic participation.
- If Feros Care doesn't already have one, we suggest it establishes an ACT participant advisory group.
- We made comment earlier that respondents to DRG survey requests and discussions want a direct link to planners. People are well-disposed to the idea of local area coordination, as it is currently understood. Participants are concerned, however, that third parties of any type must not become gatekeepers or hoops to jump through to reach a planner or any other NDIA decision-maker. There is some fear that this risk is already real.
- The LAC as described by the Productivity Commission has an important role in connecting people who are not eligible for individual plans to mainstream supports, providing information and support to the wider community to ensure disability accessibility. With the devolution of NDIA planner functions into the role of the LAC, these important functions are at considerable risk of being de-prioritised.

GOVERNANCE OF THE NDIS

We have little to add to the contextualizing comments we made regarding the NDIA in the ACT. But we do wish to make one matter explicitly clear.

The NDIS is a partnership between all the governments of Australia. Whatever the detailed architecture of the joint venture might be at any given moment, the principle we support is that of a fully-functioning intergovernmental partnership. From some perspectives the governance arrangements for the NDIS appear cumbersome. Others believe that the current arrangements are necessary, proportionate and a strength. There is merit in both cases.

Streamlined or 'as it is now'? is a worthwhile question to ask about the NDIS / NDIA. The essential characteristic, however, must be partnership.

The NDIS is a truly national enterprise. It is a human services infrastructure reform that will benefit millions of Australian directly over decades to come. In so doing it will transform not only the lives of people with disability with an individual plan and their families. Over time we shall come to see that the NDIS benefits, modernizes, and transforms Australia.

Big ideas need buy-in.

Federal, State and Territory governments have signed up to a governance partnership that means no single stakeholder can or should regard the NDIS as 'theirs'. We are not pretending, however, that there will be no moments of tension within that partnership.

The decision to establish the NDIA as an autonomous agency with an independent Board was the right one. By remaining subject to Ministerial direction in accordance with the strategic decisions of COAG and the Disability Reform Council appropriate democratic accountability is in place. But the Board has its role to exercise collective good judgment to oversee the

development and sustainability of the scheme. The senior leadership of the Agency makes its legitimate operational decisions within that framework.

The decision to create an Independent Advisory Council with some crossover with membership of the NDIA Board was also a good idea. The different roles of the IAC and the Board strengthen a productive partnership.

Perhaps the only revision we might now suggest deserves some consideration relates to the position and role of NDIS participants in the governance structure. When the current governance arrangements were established there were no NDIS participants. By now there may be 160,000 to 180,000. There will soon be 475,000.

Participants should have a formal role in governance of the NDIS. Choice & Control is, after all, a founding-principled of the scheme. How any future role could be effectively incorporated into future arrangements is not something the DRG has discussed. But it is an idea worthy of serious thought.

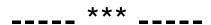
In the view of the DRG, It is essential that the ACT remains a fully-engaged partner in the future of the NDIS at Ministerial and Officer levels.

ACT Disability Reference Group 30 March 2018

Appendix 1 – DRG Submission

ACT Ratings and Responses to NDIA surveys, outcome indicators and questions As compared to National performance figures

(Source: NDIA Quarterly Report 31 December 2017)



Proportion of participants describing satisfaction with the Agency planning process as good or very good – most recent reports by quarter (ACT)

Indicator	National	ACT	Difference
2015 - 2016 quarter 1	93	100	+7
2015 – 2016 quarter 2	100	94	-6
2015 – 2016 quarter 3	100	100	0
2015 - 2016 quarter 4	95	93	-2
2016 - 2017 quarter 1	85	92	+7
2016 – 2017 quarter 2	84	79	-5
2016 - 2017 quarter 3	88	81	-7
2016 - 2017 quarter 4	84	N/A	N/A
2017 - 2018 quarter 1	84	N/A	N/A
2017 – 2018 quarter 2	83	N/A	N/A

Selected key indicators for participants 0 to 14 - ACT

- Daily Living (DL) and Choice and Control (CC)
- Relationships (REL) and Social/ Community Participation (S/CP)
- Lifelong Learning (LL),

Indicator	National	ACT	Difference
% with concerns [for child] in 6 or more of the areas: gross motor skills, fine motor skills, self-care, eating, social interaction, communication, cognitive development, sensory processing	63	41	-18
% who say their child is able to tell them what he/she wants	77	77	0
% [of children] developing functional, learning and coping skills appropriate to their ability and circumstances	30	32	+2
% who say their child is becoming more Independent	42	54	+12
% of children who have a genuine say in decisions about themselves	65	85	+20
% of [pre-school children] who can make friends with people outside the family	66	69	+3
% of [under-14] who can make friends with people outside the family	62	72	+10
% of [pre-school] children who participate in age appropriate community, cultural or religious activities	57	61	+4
% of children who spend time after	34	47	+13

school and on weekends with			
friends			
and/or in mainstream programs			
Of these, % [of pre-school	63	67	+4
children] who are welcomed or			
actively included			
Of these, % [under-14] who are	77	81	+4
welcomed or actively included			
% of children who spend time with	14	21	+7
friends without an adult present			
% of children attending school in	53	80	+27
а			
mainstream class			

Selected key indicators for participants 15 and over - ACT

- Daily Living (DL) and Choice and Control (CC)
- Relationships (REL) and Social/ Community Participation (S/CP)
- Lifelong Learning (LL),

Indicator	National	ACT	Difference
% who are happy with the level of	40	39	1
independence/control they have			
now			
% [of 15 to 24] who choose who	34	51	+17
supports them			
% [25 and over] who choose who	52	68	+12
supports them			
% [15 to 24] who choose what	44	61	+17
they do each day			
% [25 and over] who choose what	62	79	+17
they do each day			
% [15 to 24] who had been given	22	18	-4
the opportunity to participate in a			
self-advocacy group meeting			
% [25 and over] who had been	29	20	-9
given the opportunity to			
participate in a self-advocacy			
group meeting			

% [15 to 24] who want more choice and control in their life	77	73	-4
% [25 and over] who want more choice and control in their life	71	70	-1
% [15 to 24] with no friends other	28	22	-6
than family or paid staff % [25 and over] with no friends	26	26	0
other than family or paid staff			
% [15 to 24] who have been actively involved in a community,	32	34	+2
cultural or religious group in the			
last 12 months			_
% [25 and over] who have been actively involved in a community, cultural or religious group in the last 12 months	36	37	+1
% [15 to 24] who are happy with their home	82	78	-4
% [25 and over] who are happy with their home	77	71	-6
% [15 to 24] who feel safe or very safe in their Home	86	83	-3
% [25 and over] who feel safe or very safe in their home	78	68	-10
% [15 to 24] who rate their health as good, very good or excellent	69	62	-7
% [25 and over] who rate their health as good, very good or excellent	50	42	-8
% [15 to 24] who did not have any difficulties accessing health services	68	75	+7
% [25 and over] who did not have any difficulties accessing health services	68	61	-7
% who currently attend or previously attended school in a mainstream	27	59	+32

class			
% who participate in education,	14	17	+3
training or skill development			
Of those who participate, % who	48	79	+31
do			
so in mainstream settings			
% unable to do a course or	34	45	+11
training			
they wanted to do in the last 12			
months			
% [15 to 24] who have a paid job	18	28	+10
% [25 and over] who have a paid	27	31	+4
job			
% [15 to 24] who volunteer	13	14	+1
% [25 and over] who volunteer	13	16	+3

Selected key indicators for families/ carers of participants (all age groups) - ACT

Indicator	National	ACT	Difference
% [0 to 14] receiving Carer	26	11	-13
Payment			
% [15 to 24] receiving Carer	29	23	-6
Payment			
% [25 and over] receiving Carer	22	17	-4
Payment			
% [0 to 14] receiving Carer	56	19	-37
Allowance			
% [15 to 24] receiving Carer	51	33	-18
Allowance			
% [25 and over] receiving Carer	32	50	+18
Allowance			
% [0 to 14] working in a paid job	45	55	+10
% [15 to 24] working in a paid job	47	65	+18
% [25 and over] working in a paid	32	50	+18
job			
Of those [supporting 0 to 14] in a	74	86	+12
paid job, % in permanent			
employment			
Of those [supporting 15 to 24] in a	74	78	+4
paid job, % in permanent			
employment			
Of those [supporting 25 and over]	78	89	+11
in a paid job, % in permanent			
employment			
Of those [supporting 0 to 14] in a	77	83	+6
paid job, % working 15 hours or			
more			
Of those [supporting 15 to 24] in a	84	77	-7
paid job, % working 15 hours or			
more			
Of those [supporting 25 and over]	85	83	-2
in a paid job, % working 15 hours			
or more			

% [supporting 0 to 14] who say they (and their partner) are able to work as much as they want	41	51	+10
% [supporting 14 to 24] who say they (and their partner) are able to work as much as they want	47	66	+19
% [supporting 25 and over] who say they (and their partner) are able to work as much as they want	60	51	-9
Of those unable to work as much as they Want [supporting 0 to 14], % who say the situation of their child/family member with disability is a barrier to working more	86	83	-3
Of those unable to work as much as they want [supporting 15 to 24], % who say the situation of their child/family member with disability is a barrier to working more	89	Sample too small	N/A
Of those unable to work as much as they want [supporting 25 and over], % who say the situation of their child/family member with disability is a barrier to working more	85	95	+10
Of those unable to work as much as they want [supporting 0 to 14], % who say insufficient flexibility of jobs is a barrier to working more	39	27	-12
Of those unable to work as much as they want [supporting 15 to 24], % who say insufficient flexibility of jobs is a barrier to working more	34	Sample too small	N/A

Of those unable to work as much as they want [supporting 25 and over], % who say insufficient flexibility of jobs is a barrier to working more	24	10	-14
% [supporting 0 to 14] able to advocate for their child/family member	79	88	+9
% [supporting 15 to 24] able to advocate for their child/family member	74	87	+13
% [supporting 25 and over] able to advocate for their child/family member	71	91	+20
% [supporting 0 to 14] who have friends and family they see as often as they like	45	52	+7
% [supporting 15 to 21] who have friends and family they see as often as they like	45	56	+11
% [supporting 25 and over] who have friends and family they see as often as they like	48	52	+4
% [supporting 0 to 14] who feel very confident or somewhat confident in supporting their child's development	86	87	+1
% [supporting 15 to 24] who know what their family can do to enable their family member with disability to become as independent as possible	45	65	+20
% [supporting 15 to 24] who feel in control selecting services	42	65	+17
% [supporting 25 and over] who feel in control selecting services	46	43	-3
% [supporting 25 and over] who have made plans (or begun to make plans) for when they are no	39	34	-5

longer able to care for their family member with disability			
% [supporting 0 to 14] who rate their health as good, very good or excellent	72	77	+5
% [supporting 15 to 24] who rate their health as good, very good or excellent	62	69	+7
% [supporting 25 and over] who rate their health as good, very good or excellent	59	72	+13

Results for "Has the NDIS helped?" questions answered at review, for SFOF version 'Participant 0 to school' (n=105) – ACT

Question	National	ACT	Difference
	% Y	ES	
Has the NDIS improved your	92	97	+5
child's development?			
Has the NDIS improved your	90	94	+4
child's access to specialist			
services?			
Has the NDIS helped increase	82	84	+2
your child's ability to			
communicate			
what they want?			
Has the NDIS improved how your	74	73	-1
child fits into family life?			
Has the NDIS improved how your	62	66	+4
child fits into community life?			

Results for "Has the NDIS helped?" questions answered at review, for SFOF version 'Participant school to 14' (n=121) – ACT

Question	National	ACT	Difference
	% Y	ES	
Has the NDIS helped your child to	52	53	+1
become more independent?			
Has the NDIS improved your	35	32	-3
child's access to education? 32%			
Has the NDIS improved your	43	49	+6
child's relationships with family			
and			
friends?			
Has the NDIS improved your	43	45	+2
child's social and recreational			
life? 45%			

Results for "Has the NDIS helped?" questions answered at review, for SFOF versions 'Participant 15 to 24' (n=100) and 'Participant 25 and over' (n=569) – ACT

Question	National	ACT	Difference
	% YES		
Has the NDIS helped you [15 to	62	61	-1
24] have more choices and more			
control over your life?			
Has the NDIS helped you [25 and	68	75	+7
over] have more choices and			
more control over			
your life?			
Has the NDIS helped you [15 to	60	55	-5
24] with daily living activities?			
Has the NDIS helped you [25 and	72	77	+5
over] with daily living activities?			
Has the NDIS helped you [15 to	56	46	-10
24] to meet more people?			
Has the NDIS helped you [25 and	54	50	-4
over] to meet more people?			
Has your involvement [15 to 24]	25	13	-12
with the NDIS helped you to			
choose a home that's right for			
you?			

Has your involvement [25 and over] with the NDIS helped you to choose a home that's right for you?	34	21	-13
Has your involvement [15 to 24] with the NDIS improved your health and wellbeing?	43	50	+7
Has your involvement [25 and over] with the NDIS improved your health and wellbeing?	53	60	+7
Has your involvement [15 to 24] with the NDIS helped you to learn things you want to learn or to take courses you want to take?	43	26	-17
Has your involvement [25 and over] with the NDIS helped you to learn things you want to learn or to take courses you want to take?	34	26	-8
Has your involvement [15 to 24] with the NDIS helped you find a job that's right for you?	22	20	-2
Has your involvement [25 and over] with the NDIS helped you find a job that's right for you?	21	16	-5
Has the NDIS helped you [15 to 24] be more involved?	58	47	-11
Has the NDIS helped you [25 and over] be more involved?	62	59	-3

Results for "Has the NDIS helped?" questions answered at review, for SFOF version 'Family 0 to 14' (n=199); and for SFOF versions 'Family 15 to 24' and 'Family 25 and over' combined (n=35) – AC

Question	National	ACT	Difference
	% Y	% YES	
Has the NDIS improved your	55	57	+2
capacity [0 to 14] to advocate			
(stand up) for your child? / Has			

		,	
the NDIS helped you to know your rights and advocate effectively?			
Has the NDIS improved your capacity [15 and over] to advocate (stand up) for your child? / Has the NDIS helped you to know your rights and advocate	45	23	-22
effectively? Has the NDIS improved the level of support for your family [0 to 14]?	63	68	+5
Has the NDIS improved the level of support for your family [15 and over]?	56	41	-15
Has the NDIS improved your access to services, programs and activities in the community [0 to 14]? / Has the NDIS helped you to access services, programs and activities in the community?	65	73	+12
Has the NDIS improved your access to services, programs and activities in the community [15 and over]? / Has the NDIS helped you to access services, programs and activities in the community?	55	48	-7
Has the NDIS improved your ability / capacity to help your child develop and learn?	70	77	+7
Has the NDIS improved your health and wellbeing [0 to 14]?	40	43	+3
Has the NDIS improved your health and wellbeing [15 and over]?	33	47	+14