

**NLS**

**National Institute of Labour Studies
Flinders University, Adelaide, Australia**



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Evaluating the Impact of the NDIS

Financial Sustainability for the NDIS

Sydney 30 – 31 May 2017

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Acknowledgements

The independent evaluation of the trial of the NDIS trial is led by the National Institute of Labour Studies at Flinders University and funded by the Australian Government Department of Social Services (DSS)

Deep thanks go to the thousands of evaluation participants who are sharing their experiences with the research team, to our research partners, to the DSS for their strong support, and to the evaluation's research team for their high quality work and dedication

<http://ndisevaluation.net.au>

Sustainability of the NDIS

- Sustainability is not an either-or concept and can be viewed through several lenses.
- For example, the NDIS sustainability is:
 - Multifaceted
 - Is the NDIS 'living within its means'?
 - Is the NDIS balancing competing interests?
 - Is the NDIS protective of systemic safeguards?
 - Evolving
 - Teething attributes and longer term systemic problems are not the same
 - When can we expect the NDIS to 'settle'?

It is all about change!

Change and the NDIS

- As the NDIS evolves, there is no simple/single answer to the question of “whether the NDIS is sustainable”
- Best to identify and observe where change happens and see what it does to performance
- Example questions we could/should ask:
 - What are the changes that may matter for future sustainability?
 - How are they developing over time? Pointing in the right direction?
 - Can we Identify and track teething *versus* systemic problems?
 - How are all stakeholders perceiving change and responding to it?
 - and more...

Outline of this talk

- The critical importance of data to monitor change
- The NDIS evaluation and its data/evidence base
- Focus on sustainability based on published evidence on:
 - Unmet demand
 - Choice and control
 - Wellbeing and socioeconomic participation
- Implications about economic and institutional outcomes
- Ongoing work and future needs and outputs

Where is the evidence coming from?

- This talk uses evidence published in the Intermediate Report of the NDIS trial areas evaluation
- The evaluation touches directly and indirectly many aspects of the roll out relating to sustainability
- The NDIS evaluation is a unique source as its collection is:
 - Large scale and Independent
 - Broadly covers all relevant stakeholders
 - By the end of 2017 it will have followed the first 4 years of the NDIS' roll out and development

A few more words on the Evaluation, its Purpose and its Outputs to date

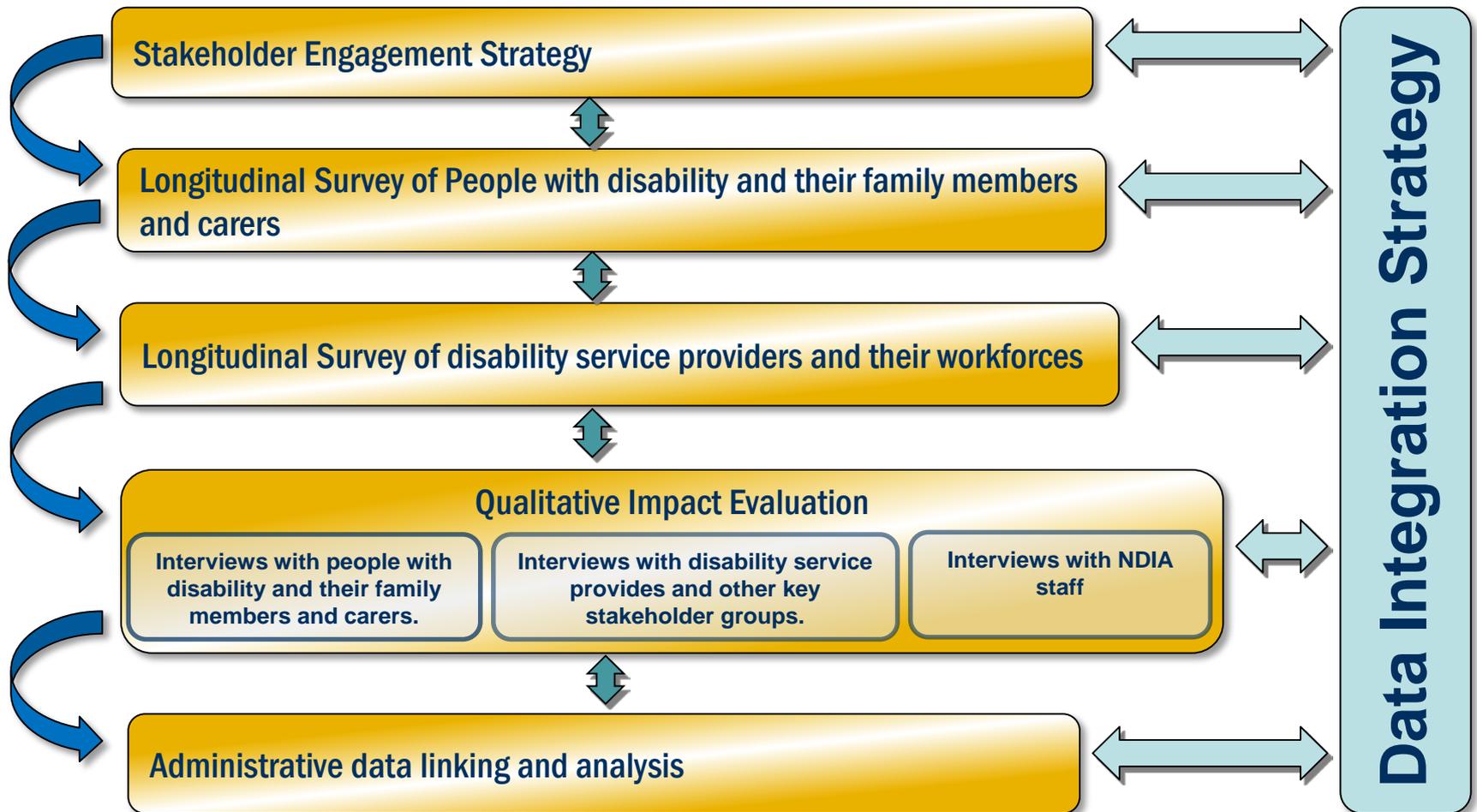
What the Evaluation does

- It measures the impact of the NDIS roll out in the trial areas (except WA and QLD) over a 3-4 year period (2013-17) on:
 - People with disability and their families and carers
 - The disability sector (employers and workers)
 - A broad range of other stakeholders
- It collects information over time (longitudinal) and studies change
- It is the first national longitudinal survey of people with disability and their families and carers and is the only independently collected large scale data source following disability and the NDIS in Australia

The Core Evaluation Components

- Overarching Stakeholder Engagement Strategy
- Longitudinal survey of people with disabilities & family members and carers (close to 8,000 interviews in wave 1)
- Longitudinal survey of disability service providers and their workforces (close to 3,000 interviews in wave 1)
- Extensive Qualitative Impact Evaluation
- Several other studies (NT; Older People; Mainstream)
- Data integration, linking, econometric impact analysis, and reporting

Integrating the NDIS Evaluation Components



Key Evaluation Reporting

- **Initial Report** – describes the first stage of the evaluation, focussing on setting up, ethics, design and methodology
<https://www.dss.gov.au/disability-and-carers/programs-services/for-people-with-disability/national-disability-insurance-scheme/ndis-evaluation-intermediate-report>
- **Intermediate report** – Policy-oriented provides first evidence and discussion <https://www.dss.gov.au/disability-and-carers/programs-services/for-people-with-disability/national-disability-insurance-scheme/ndis-evaluation-intermediate-report>
- **Final Report** – is scheduled to be delivered in 2017 and will complete the 2013 – 2017 evaluation.

The purpose of this talk

- To explain how the Intermediate Report can be used as a navigation tool by those who wish to know more about the change that is taking place
- We use the following example aspects of the change brought by the NDIS and their impacts:
 - **Supply and demand** of support services
 - **Choice and control** (including self-management)
 - **Wellbeing, Participation** (social, economic and educational), and **Aspirations** (goals)
- We integrate (qualitative + quantitative) evidence

Supply and demand of support services

- A system that does not produce the required and planned quantity and quality of supports can be challenged
- Many reasons why supply may not be able to meet demand, some temporary and manageable, some structural, systemic, and long-term
- Some may be of economic nature, some institutional and some mixed
- The Evaluation collects information on the views of many stakeholders about imbalances in demand and supply

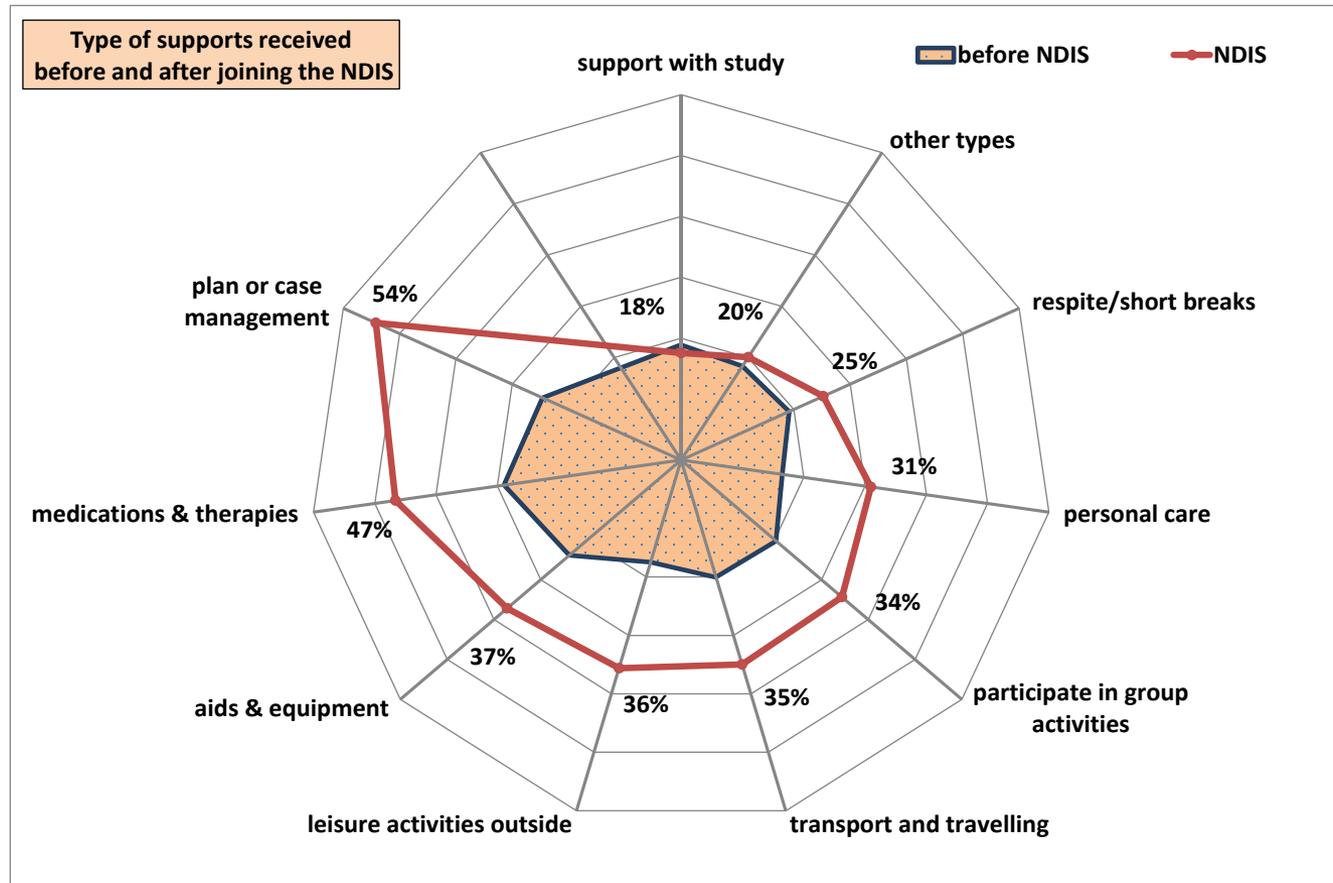
Supply and demand of support services:

Selection of Key Evaluation Questions (KEQs)

- KEQ 17: For people with disability who previously received supports, to what extent has the NDIS contributed to changes in their patterns and use of supports?
- KEQ 32: What has been the impact of the NDIS on the overall provision and quality of disability services?
- KEQ 34: What has been the impact of the NDIS on the disability sector, including the relevant government agency in each jurisdiction and advocacy organisations?
- KEQ 35: Consider impacts on workforce (skills, retention rates, capacity, satisfaction, workforce culture, composition and proportion of occupation types).
- KEQ 36: Consider impacts on supply and diversity of disability supports (particularly sustainability, ability to respond to choice and control, and service capacity).
- KEQ 37: To what extent has the supply of disability services responded to demand?

Where did additional demand go?

Pre-NDIS (**black line**) and after joining the NDIS (**red line**) types of supports - % of people receiving each type of support



Demand for supports: **Is demand met?**

- Combined qualitative and quantitative data on NDIS participants indicate that:
 - Most NDIS participants need assistance on a daily basis, but just **under 1/3rd utilise market provisions** for it
 - Most receive **increased supports due to the NDIS** (hours, frequency, more appropriate equipment, wider access)
 - Majority report **increased satisfaction with their supports** after joining the NDIS; (a small minority report lowered satisfaction)
 - For most, the number/variety of supports received has increased (**65% increase in number of support types pre/post NDIS**). But many have remained with the same provider(s) [**61% Trial respondents remained against 78% Comparison respondents**]. Some indication of changing providers once familiar with the system, but is not conclusive as yet

- **Looking at findings a bit closer [interpretation]:**
 - Most NDIS participants need assistance on a daily basis, but just **under 1/3rd utilise market provisions** for it [markets appear to be slow]
 - Most receive **increased supports due to the NDIS** (hours, frequency, more appropriate equipment, wider access) [institutions work, increasing supports]
 - Majority report **increased satisfaction with their supports** after joining the NDIS; (a small minority report lowered satisfaction) [a core objective seems to be achieved, people feel better off after joining the NDIS]
 - For most, the number/variety of supports received has increased (**65% increase in number of support types pre/post NDIS**). But many have remained with the same provider(s) [**61% Trial respondents remained against 78% Comparison respondents**]. Some indication of changing providers once familiar with the system, but is not conclusive as yet [more supports in number and variety]

On average, we see a positive picture!

But the devil is in the detail...

The “good” averages (in the overall picture) also include individuals or specific sub-groups who report their outcomes became worse after joining the NDIS. The better averages conceal dissatisfaction:

- Examples of dissatisfied NDIS participants:
 - Among participants who are unable to effectively **advocate on their own behalf** (fewer supports and poorer outcomes)
 - Participants in **rural and remote** areas (unmet demand)
 - Older or younger (variable for some supports)
 - In **finding** and/or **getting** supports
 - In doing the **necessary paperwork**
 - In **accessing supports** even when funding is in place

Averages conceal the diverse reality of winners and losers

Cases where reported Supply and Demand were not in equilibrium

- Cases where supply is not meeting demand
 - **providers cease to supply** services they consider to have become underfunded under current NDIA cost guidelines
 - exacerbate the risk of market shortages and can **increase the prices** of uncapped supports and/or **decrease the quantities** of price-capped supports.
- Cases where NDIS participants continue to access supports that are not funded in their NDIS plan.
 - Such **unfunded supports** include alternative therapies and social and recreational activities. It is reported that NDIS participants and/or their family already pay **out-of-pocket expenses** for accessing such services.

Careful reading of the report reveals the experiences of thousands of people who became NDIS participants.

Choice and control (including self-management)

Choice and control: KEQs (including self-management)

- KEQ 4: To what extent has the NDIS enabled people with disability, their families and carers to have increased choice and control over their supports?
- KEQ 5: To what extent did people have increased choice and control over the development and implementation of their plan?
- KEQ 8: How have people responded to increased choice and control?
- KEQ 15: To what extent have people with disability, their families and carers been able to manage their funding on their own, customise creative sets of options for themselves, or find suitable brokers, depending on their preferences?
- KEQ 22: What sort of assistance do people with disability (or their families and carers, if they are managing the care) require to gain more control and navigate the system?

Choice and Control: **NDIS participants**

- Overall improvement in choice and control over supports:
 - about half indicate that they are **better off** than before the NDIS
 - about one third indicate that they are **about the same**
 - about 15 per cent indicate that they are **worse off**

Roughly for each question we get 50% better off; 35% about the same; 15% worse off

Diversity among the 15% who report being worse off.

Choice and Control: NDIS participants like the increase, but want more

- There is a clear **desire for more choice and control** over supports
 - NDIS participants and their family members and carers desire:
 - **More information** about available services
 - **Help with defining factors** on which they can base their choice
 - **Improving the NDIA website**, often reported to be difficult to navigate, inhibiting access to information
 - **Improving** choice and control where it may be restricted by limitations in the **number or the capacity of service providers**

Desire for more consumer-directed provision

Case Management: NDIS participants

- Case management/case coordination is valued – There are cases where it removes the burden and stress of communicating and co-ordinating with providers
- Self-management is very uncommon
 - reluctance to take on additional administrative activities

However,

- those who did self-manage, experienced greater choice

Choice and Control: family members and carers

- Overall, a **positive picture**:
 - **NDIS increases the ability** of family members and carers **to care** for people with disability
 - In the quantitative data large numbers of family members and carers report **high levels of satisfaction with the amount of say they have** about what supports the person with disability receives and where they obtain those supports

Choice and Control: family members and carers

- However, **concerns** are also expressed by families that family needs are ignored or addressed inconsistently
 - The qualitative data - family members and carers own needs and the needs of the family more broadly were not addressed. **Greater attention to the family needs requested**
 - Both the quantitative and qualitative data indicate that family members and or carers are **unable to take adequate breaks** from providing support and that they **cannot access carer support in a consistent manner**

Wellbeing, Participation (social, economic and educational), and Aspirations (goals)

Wellbeing, Participation (social, economic and educational), and Aspirations (goals)

- KEQ 1: To what extent has an NDIS contributed to changes in wellbeing and quality of life for people with disability, their families and carers?
- KEQ 2: To what extent has the NDIS contributed to changes in social and economic participation (including employment, education and the ability to express wishes and have them respected) for people with disability, their families and carers?
- KEQ 3: To what extent has an NDIS enabled people with disability, their families and carers to achieve their goals?
- KEQ 24: To what extent has the NDIS helped people with disability, their families and carers during major life transitions such as starting preschool or school, leaving school, starting tertiary education, starting work, leaving home, leaving state care, leaving the workforce, and entering the aged care system?
- KEQ31: Have there been any other changes, including unintended changes (anticipated and unanticipated, positive and negative), in the experiences of people with disability, their families and carers as a result of the Scheme?

Lower levels of Wellbeing

- We use the survey data to calculate the **Personal Wellbeing Index** (PWI) for each respondent
- NDIS participants overall have a **much lower average wellbeing index than the national average** in Australia
- **Lower levels** of wellbeing are reported especially by:
 - NDIS participants with a **mental health or psychosocial disability**.
 - Those who experience **unmet demand for supports**
 - Those who have **less choice over supports**.

Wellbeing **is improving**

- Just under half of all family members and carers report that they experienced **financial hardship over the last 12 months**
- It is essential to assess whether the NDIS improves the personal wellbeing through ameliorating financial hardship
 - The second wave of the quantitative survey data will enable this assessment
- The two waves of qualitative evidence have provided early but non-generalisable indications of improved wellbeing
 - On the whole the NDIS is reported to have improved the wellbeing of its participants and that of their family members and carers

Social participation **is increasing**

- For many **NDIS participants** social participation has increased, in that they have become:
 - Able to **take part in activities independently** (i.e. without the support of a family member)
 - Able to have **access to support when needed**
 - Able to **follow previously inaccessible interests and social activities**
 - Able to **visit friends and family** or to have people to stay
- **Easing the care burden on family members and carers**, widely improved their social participation (it allowed them to be involved in other valued activities that would have not been possible previously)

Social participation is increasing, **but not for all**

- Social participation benefits are not spread evenly, for example:
 - Increases in social participation were **limited** in the case of NDIS participants with
 - **mental health** problems,
 - **intellectual disabilities**, or
 - with **Autism Spectrum Disorder**

Same old complaint... Many people are left behind...

Educational participation

- Education is high on the agenda
- High number of NDIS participants were currently in education
 - **Mainly to get a job**
- Around a quarter of those not studying would like to be, but their own health or disability was preventing them from doing so
- Very few family members and carers were currently studying

Employment and economic participation

- Employment is high on the agenda
- A fifth of all NDIS participants were currently employed and largely liked their jobs, however their employment does not appear to be stable
- Large proportion of those not in employment would like to hold a job, but the **reported barriers to getting a job appear to be formidable**

Employment and economic participation are very important, but they remain long-term aspirations and goals for most

We also identify several unintended consequences

- Below is a selection
 - NDIS **funding of individualised support** services instead of group-based services had negatively impacted on the social participation of some NDIS participants who no longer attended programs where they had previously mixed with a range of people
 - **Support for carers** (within and outside of the NDIS) has diminished since the NDIS roll-out
 - Concerns about the impact the NDIS would have on **people with disability not eligible for the NDIS**. Some reported to be receiving fewer services while others were falling through service gaps and getting no supports at all

Summing up remarks

We find complexity and rapid change

We find most participants are clearly better off, but many become worse off after joining the NDIS

Sustainability may be impacted on, if the present system leaves many people behind as our evidence clearly shows

We examine many “who, why, how, how long for” questions

The evaluation continues to collect valuable independent evidence and will report on its full findings end 2017

How can our evidence guide improvement?

By identifying and quantifying the differences in the way the NDIS impacts on different people and families

By contrasting the demand information with the supply information from people and providers/workforces

By conducting careful analyses to form an independent and holistic body of knowledge on the evolution and performance of the NDIS.

Individuals, family members, providers, everyone can be guided in their efforts to combat the unwanted impacts of the NDIS and reinforce the many desired impacts

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Supplementary material on data
collections: Please read on...

An important note about the NDIS Evaluation's data

Without **strong and independent data** it will be difficult to evaluate the new consumer directed care policy

This is why we spent much effort to generate new and innovative data on disability

The evolution of the NDIS will depend on the presence and use of high quality and large scale information to monitor performance and outcomes

Please read on...

Forthcoming data collections: June 2017+

We are beginning **new fieldwork**, asking people with disability, and their families and carers, as well as employers their employees and the self employed in the sector for their recent NDIS experiences

Building the longitudinal element of the data will enhance hugely our capability to guide development

We will be in the field for several months

For details please see <http://ndisevaluation.net.au/>

Also see re-contact postcard (not in scale) to be sent to all people with disability and their families and carers

An update from the NDIS Evaluation Team

We are deeply grateful to all participants of the NDIS Survey for generously giving their time and for sharing their personal experiences.

The National Institute of Labour Studies (NILS) at Flinders University is carrying out the only independent evaluation of the NDIS. Our independence is very important for getting a good and accurate picture of what is happening as the NDIS is rolled out.

You will soon be sent your second NDIS Survey or NDIS Survey for Families and Carers so that we can find out how things have changed since you last did the survey. Roy Morgan Research is undertaking the second NDIS Survey for NILS.

We hope that you will continue to tell us about your experiences. By hearing from the people who are most affected we can build a detailed picture about the roll-out of the NDIS.

The first two reports from the evaluation have been publicly released - details on other side.

NDIS Evaluation

Find out about the NDIS Evaluation at www.ndisevaluation.net.au

Since the start of the NDIS Survey we've heard from...

- 4,429 people with disability
- 3,386 family members & carers

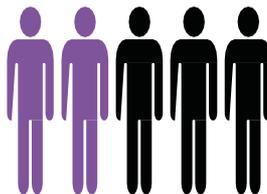
NDIS Survey participants are contributing to a comprehensive body of evidence about disability in Australia for the independent evaluation of the NDIS.

Of the NDIS participants surveyed:

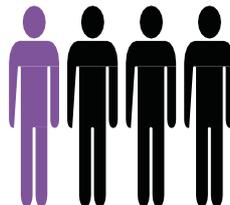
The majority of clients in the NDIS have enjoyed greater choice and control and increased supports, but some reported having difficulties with the Scheme.

The average number of supports accessed by individuals has increased from 2.2 to 3.3.

- More than 2 in 5 people (44%) reported having more say over the supports they received



- About 1 in 4 people (27%) could not access some of the supports for which they had NDIS funding



The Initial Report has all the facts that we have collected so far, from surveys and interviews with people with disability, and their families and carers, peak body organisations, NDIA staff, disability support providers and their workers, and other stakeholders.

The Intermediate Report has our analyses of the facts that we collected in the surveys and interviews, building a picture of how the NDIS roll-out is going and the impacts.

You can access the reports from links on the NDIS Evaluation website www.ndisevaluation.net.au

For enquiries about the NDIS Survey please call 1800 155 676 or email ndissurvey@roymorgan.com

Why we ask for your support to achieve higher response rates:

The evaluation gives a voice to stakeholders: thousands of people with disability and their families and carers, and to thousands of support providers and their employees

The evaluation's research will help improve NDIS outcomes and guide relevant policy

The evaluation produces set of new disability-specific large scale national surveys: (i) of people with disability and their families and carers and (ii) providers and their workforces

The evaluation is an independent national exercise, designed to monitor objectively and sensitively how well the NDIS is doing

Please make sure you help us create the evidence that will help the development of a stronger NDIS

Thank you!

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