

Positive Outcomes of NDIS Participation

23 Individual Case Studies

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Purple Orange

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Preface

JFA Purple Orange is an independent, social-profit organisation that undertakes systemic policy analysis and advocacy across a range of issues affecting people living with disability and their families.

Our work is characterised by co-design and co-production, and includes hosting a number of user-led initiatives.

Much of our work involves connecting people living with disability to good information and to each other. We also work extensively in multi-stakeholder consultation and collaboration, especially around policy and practice that helps ensure people living with disability are welcomed as valued members of the mainstream community.

The work of JFA Purple Orange is anchored on the principles of Personhood and Citizenship.

As set out in our *Model of Citizenship Support*¹, a good life is characterised by such valued roles (termed Citizenship) and by the decisions we make (termed personhood). A good life largely depends on the availability of life chances – the assets and opportunities available to a person.

Unlike formal citizenship of a country, Citizenship is a dynamic experience: it can rise and fall depending on a person's circumstances. The extent to which any person can naturally take up Personhood and Citizenship is influenced by the presence of circumstances that can adversely impact on the person's capacity to build authorship of their own lives and the person's capacity to take up valued roles in community life and the economy.

Aside from the need to increase the total amount of funds available for disability support, the two values that have driven the emergence of the NDIS have been:

1. Each person having control and choice, taking up authorship of their own life.
2. Each person participating in community life and the economy, taking up valued roles that bring genuine community membership.

These NDIS values have an excellent fit with the notions of Personhood and Citizenship. The NDIS is founded on a framework that promotes the empowerment of people living with disability.² As such, JFA Purple Orange believes that all eligibility and access to services provided by the NDIS must be anchored on principles that will assist people to feel empowered and supported, and to take up valued roles in mainstream community life.

¹ Williams, R. (2013), *Model of Citizenship Support: 2nd edition*, Julia Farr Association Inc, Unley, South Australia.

² NDIS Values, Capabilities, and Behaviours factsheet, <https://www.ndis.gov.au/about-us/careers-ndia/values>

Abstract

This publication reports on survey data collected in 2018 from 94 people who are current National Disability Insurance Scheme (NDIS) participants.

Key findings included identifying significant positive outcomes for participants as a result of their involvement in the scheme.

This paper discusses the way in which these outcomes are helping people to advance their lives and makes recommendations regarding measurement of the scheme and its benefits to participants.

Introduction

In October 2018, JFA Purple Orange undertook a survey to identify the different experiences and outcomes that NDIS participants have had during their time accessing the scheme.

The survey was powered by Survey Monkey and was shared across online and community networks, including social media. The survey was open to anyone who is a participant in the NDIS across Australia, or someone responding on behalf of an NDIS participant.

The survey was mostly open-ended in structure and covered aspects of the NDIS participant pathway, such as:

- initial access to the NDIS
- preparation for plan meetings
- experience of plan meetings
- identifying goals
- ways in which NDIS experience has been positive or beneficial
- ways in which needs are still not being met.

This research report is the first in a series of planned publications detailing the different experiences we heard about from our survey.

This report focuses on examples of positive gains, benefits and ways in which NDIS participant life chances have improved from participation in the scheme. We hasten to explain to our readers that we are not suggesting that all of the experiences of the participants who feature in our case studies have been wholly positive. Rather, these case studies provide examples of the ways in which participants have experienced significant benefits through their NDIS involvement. Future publications will focus on practical issues that participants have identified as factors they are concerned by.

Methodology

Process

The survey comprised 24 separate questions, which covered demographic information and NDIS access experiences, and then open-ended questions relating to participant pathway experiences, which allowed respondents to provide free text replies with no word limit.

The survey was circulated using a snowball sampling process of online promotion, email alerts and word of mouth.

Participants

Participants comprised 94 people living with disability or people completing the survey on behalf of someone living with disability. Of the responses received, 27% were from people living with disability, while 73% were from people responding on behalf of someone living with disability, including on behalf of children. Participants ranged in age from children to between 55 and 64 years of age. Participants were located in South Australia, Victoria, New South Wales, ACT and Queensland, with the majority being located in South Australia (74%).

Ethical considerations

Data was de-identified prior to data analysis. All data has been stored confidentially and will be reported in a way that ensures identification of participants is not possible. Participants were able to answer which questions they wished to respond to, and could choose to exit the survey at any time. The survey took approximately 10 minutes to complete.

Limitations

We recognise that this data has been collected via self-report questionnaire for all participants and therefore researchers cannot guarantee factual accuracy.

Data analysis

All data was thematically analysed by the project leader. Demographic data, including education, employment and type of disability, has been collected and analysed, but this is only included in reporting where relevant to the themes being discussed.

A series of in-depth case studies of examples of experiences with NDIS participation have been created.



Findings

Demographic data

Respondent gender	Total
Male	44
Female	49
Other	1
Total n	94

Primary disability category of respondent	Percentage and number of respondents
Physical	21.28% (20)
Intellectual	21.28% (20)
Neurological	34.04% (32)
Acquired brain injury	10.64% (10)
Developmental delay	3.19% (3)
Psychosocial	5.32% (5)
Hearing	2.13% (2)
Vision	1.06% (1)
Speech	1.06% (1)
Total n	94

	Total n
Percentage and number of respondents who live with disability	25
Percentage and number of responses contributed on behalf of someone living with disability	69
Number of responses contributed on behalf of someone under 18 years old	39
Number of respondents identifying as having CALD background	11

Spread of respondent age ranges	Total <i>n</i>
less than 18	39
18 to 24	12
25 to 34	7
35 to 44	10
45 to 54	17
55 to 64	7
65 to 74	2
Total	94

Prior disability support experience	Total <i>n</i>
Was already receiving funded disability supports	27
Was a recipient of a disability support pension	26
Received no funded supports or pensions for disability	34
Accessed NDIS through Access Request Form	45
Transitioned from existing service	36
Unsure of how NDIS access occurred	5

Employment experience	Total <i>n</i>
Is under 18	39
I have never been employed	16
Has own business or enterprise	2
I work full-time	1
I work part-time	6
I work on a casual basis	2
Works at an ADE	3
Currently seeking employment	2
Not currently seeking employment but would like to work	4

Case studies

Examples of significant outcomes from participation in the NDIS

The following case studies have been created following analysis of survey data. All identifiable information has been removed.

These case studies provide examples of positive benefits stemming from NDIS participation. All quotations are taken directly from survey data and are reported verbatim.

Case study 1

Background:

- A young man aged between 18 and 24 living with intellectual disability and autism.
 - Lives in a large capital city with family.
 - Speaks both English and Chinese, with family speaking only Chinese at home.
 - Did not complete high school.
 - Is a recipient of the Disability Support Pension.
 - Has been a participant in the NDIS for less than a year, after transitioning from an existing disability service.
 - Mother helped to fill out this survey.
-

“The way that my disability most impacts me is that I have been unable to access social, community and recreational activities by myself, I have a lack of communication skills, I have no friendships, I am unable to look after myself, and I have experienced bullying.”

“In regards to my initial meeting for my NDIS plan, I thought that my LAC was friendly and patient as she tried hard to get me to answer some questions. She listened to what I said without interrupting me and that made me comfortable and relaxed. My goals are clear for me, though I dislike cooking but Mom said it’s important for me to learn as it is a skill needed for living independently!”

“My NDIS funding has helped me to be more involved in the community because I am able to get out of my house more often under the help of support workers; for example, trying ice-skating for the first time in my life! I am also able to get out of the house more to go visiting places that I like to go, and I have been able to learn to cook 3 recipes now (still with some support from Mom).”

“Under the NDIS I can see an exercise physiologist, which is good to help me to stay healthy and look after my well-being as well as improving my motor skills. I was funded for 4 sessions of 30mins but this funding could only fund two hours in total for the whole plan, so hopefully I get more in the future as it is helping a lot.”

Case study 2

Background:

- A 13-year-old girl who lives with intellectual disability and Prader-Willi syndrome, which affects her socially and emotionally.
- This family live in an inner-city suburban area.
- Has been a participant of the NDIS for less than a year and is on her first plan.
- Prior to accessing the NDIS, the family received no funded supports or pensions for this child's disability.
- Mother filled out the survey on behalf of daughter.

“We did a lot of preparation for our first plan meeting including engaging a paid consultant to help us with the process. The meeting was in person at an NDIS office and it went for two hours. It was a good meeting. It was straightforward as I had done the pre-planning.”

“The NDIS has been great for my daughter. She has had less meltdowns and is much happier. The increase in social and community participation has been fantastic. It has made our family life less stressful and my daughter is happier as she has a more independent life with support workers. There are still some things I would like to see in her plan, such as appropriate goals around weight loss, but overall the NDIS has been a godsend to our family. We are still working out the plan, what we can and cannot do, but we are very grateful.”

Case study 3

Background:

- A young man aged between 25 and 34 living in the outer suburbs of a large capital city.
- Lives with Down syndrome, which he describes as most affecting him through slower learning, impaired speech and weight problems.
- Has completed high school.
- Works at an Australian Disability Enterprise (ADE).
- Prior to accessing the NDIS, he was a recipient of a Disability Support Pension but was not receiving other funded supports.
- Has been an NDIS participant for one year.
- Mother helped to do this survey and it is written from both her and son's perspective.

“We have a good plan covering most vital needs; i.e., speech, fitness and health, and dietary guidance and independent living are all covered.”

“The first NDIS plan meeting was in person with a case worker, the family and representation from the workplace. It wasn't too hard to identify the goals because work and family helped me, so wasn't too hard.”

“It has taken 3 tries to get it right but now luckily he belongs to groups and so he has been able to get into social activities which make a huge difference.”

“I have got myself fitter through training and diet, which I couldn't afford before. Lost 17 k in 10 months through dietary guidance and supervised training.”

Case study 4

Background:

- A girl in Year 10 who is completely deaf, has no hearing whatsoever and cannot be assisted by any form of device.
- She is reliant on Auslan to communicate.
- She can read exceptionally well but is not as proficient in written English.
- Lives with family in the inner suburbs of a capital city. Mother helped to do this survey.
- Prior to accessing the NDIS, she received some support through Australian Hearing.
- She has been an NDIS participant for three years.

“She was transitioned to the NDIS by Australian Hearing; however, since she has no auditory nerves AH didn’t actually provide anything useful. Our first plan was to enable access to interpreting services. Her first plan was in person and was quite helpful. A plan was developed that, for a first plan, when you aren’t currently receiving supports, was considered adequate.”

“Her goals were all around accessibility with some associated psychology. We had no difficulty in her disability being recognised for what it was. We didn’t really know how much funding she would need. We didn’t even know how much an interpreter costs. We didn’t know what activities she would access once she had the funding. It was only once she started doing things that we realised the potential that the NDIS could give her.”

“Besides being deaf, she also has no balance nerve. NDIS has funded physical activities to enable her to work on this such as RDA and circus skills. NDIS has funded interpreters for many things. For example, a youth group, church attendance, science club, deaf youth activities, and some theatre performances. Also, she is vision impaired and only has one physical ear, which makes it difficult to keep glasses in place. They eventually funded special frames that do not rest on the ears. They have also finally agreed to fund a system of smoke detectors that will be appropriate for both the hearing and deaf people in the house.”

“Access to interpreters has been wonderful when there has been sufficient funding. It has opened up a world of opportunity for her that was out of reach previously. We are extremely grateful for this.”

Case study 5

Background:

- A young boy in Year 3 who lives with autism spectrum disorder.
- Lives with family in outer suburbs of a capital city.
- Has been a participant of the NDIS for one year and is on his first plan.
- Prior to accessing the NDIS, the family received no supports for this disability.
- Mother filled out the survey and the responses are written from the boy's perspective.

“My mum filled out all the pre-meeting checklists sent to us from NDIS. She set some very basic and broad goals. She was also helped by a teacher at my school so she had lots written down just in case.”

“[The initial plan meeting] was over the phone. My mum and grandpa both spoke about me and my needs with the planner. Mum was scared she would forget something so went over it lots asking and answering more questions.”

“I started fitness training at [NAME] and I love it. I have learnt that I am stronger than I realise and I like how my body feels after my sessions, but best of all I can keep up with my friends when they play chasey at lunchtime. I also get to have a counsellor who helps me figure out my feelings and emotions. I can tell him my secrets and he helps me figure out if I need to tell Mum so she can help me with them!”

“I have been able to do things I couldn't have figured out how to do myself like self-regulate my mind and body when my emotions get too big and I start to meltdown. My friends ask me to play more games because I can run around faster. I get to school late 2 mornings a week and miss subjects I don't like but not the ones I do like!”

Case study 6

Background:

- A school-age girl who lives with cerebral palsy, resulting in physical and neurological disability.
- Has no functional use of right hand and has right side hemiplegia. Also experiences cognitive challenges.
- Lives with family in inner suburbs of a capital city.
- Previously had some limited services from a large disability provider.
- Has been a participant in the NDIS for three years.
- Mother has filled out this survey from child's perspective.

“Mum did it [initial plan meeting] and found the planner good. Took along current reports from allied health providers and original diagnostic reports.”

“[The NDIS has helped me] by supporting my need for physical/occupational/speech therapy and psychology. If I do not keep up physical/occupational therapy my ability to function independently is compromised and activities become too fatiguing so I can only join less. Speech therapy helps me to communicate – both understand and express my needs – and psychology helps me to understand myself and how I fit in this world.”

“So far it [the NDIS] has been very good but I am worried if I can't keep having therapies then I can't function, like move about or get people to get me.”

“Mum says it has really, really helped us because now she doesn't have to do the therapy work and she can just be my mum. But she does nag me still with practice and now she can afford to pay for other things like dance class and uniform plus we can afford to do family activities now.”

Case study 7

Background:

- A young man who lives with physical disability, resulting in complex communication needs and use of a wheelchair.
 - Lives in a large regional Australian town.
 - Prior to accessing the NDIS, he was already receiving funded disability supports.
 - He has completed high school and now owns his own business.
 - He has been an NDIS participant for four years.
 - He transitioned into the NDIS from an existing disability program.
 - His mother has helped to fill out the survey and the responses are written from the young man's perspective.
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"My mom helped me think about goals and the future. I just thought about the things I would like to do, similar to other people my age who maybe don't have a disability. My first meeting was good. The planner listened. I got bored and my mom continued the meeting with the planner."

"[The content of the plans has been] good so far. I've had good planners who listen well and understand. My mom is good at explaining my support needs."

"I am starting my own business, practising my literacy, building my communication skills, getting out in the community every day, joining groups of people who like doing the same things as me, practising photography, going to the pub, having parties at my house, and just starting to live independent of my parents."

"I'm getting great support to do the things I want to do."

Case study 8

Background:

- A young man who lives with intellectual disability and also ASD, anxiety and sensory processing disorder.
 - Lives with family in the inner suburbs of a large capital city.
 - Prior to accessing the NDIS, he was already receiving funded disability supports.
 - Completed high school in a modified curriculum in a private special school setting.
 - He has been an NDIS participant for less than a year and this is his first plan.
 - His mother has filled out this survey and has written it from the young man's perspective.
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"I always need 1:1 support to keep myself and others safe. I find it hard to function in the world I live in. I need my mum or a support worker to talk to all the time and I need to talk about the same thing over and over, which gets on people's nerves. I feel anxious that things will go wrong. I cannot handle people not listening to me as then I think they are fobbing me off. I need to talk and have people to support me to be able to do most things."

"My mum made sure I had a pre-planning meeting and had all the information I needed. [My first plan] was in person; the lady didn't want to talk about [certain topics] so I went for a walk with my support worker and Mum did the interview. The lady did ask if it was okay with me for Mum to talk about what I needed. Mum said the lady seemed to understand and took all of the documents I had."

"[To identify my goals] Mum helped me think about the things I like to do and things I would like to try. I was very clear that I wanted to spend more time with my friends and do things I liked to do. Mum and I wrote down all the things I did then added things I would like to do, like a giant weekly planner. Then we added things I might need to make me more independent and added people I could see who could help me, like the OT and behaviour people and someone to talk to."

“[My NDIS plan] has helped me to participate in basketball better and have time to do things I like to do. It has given me the opportunity to be out and about and learn new things. I am also working with an OT to support my independence and am looking forward to a weekend away with friends soon.”

“It has been good to have the ability to get things I need and support from where I want, not to have to be tied to overpriced providers. Finally having some support for OT and psychology and behaviour support.”

Case study 9

Background:

- A boy who is currently in Year 10 and who lives with developmental delay and sensory processing disorder.
- Lives with family in a large regional area.
- Cannot currently attend school because he is in-between special school and public school programs.
- Prior to accessing the NDIS, he received no funded supports or pensions for disability.
- Has been an NDIS participant for two years and has had two plans.
- His mother has helped to complete this survey and responses are written from both perspectives.

“[My first plan meeting] was in person at my home. Planner was nice and listened to us. It was direct and helpful. Carer (Mum) helped identify goals and the planner helped as well.”

“Core support community funding has been good. And consumables. Enough [funding] to get psychology and also community activities.”

“My son has made amazing progress in two years from a child who would not leave the front fence without Mum to someone who goes on the bus home from community access day and also shops at the local stores on his own. He is making progress in life and being supported.”

Case study 10

Background:

- A young woman who lives in a regional area with vision impairment.
- Prior to accessing the NDIS, she was a recipient of a Disability Support Pension.
- She holds post-graduate qualifications.
- She works part-time.
- She has been an NDIS participant for three years and is on her fourth plan.

“As someone who had never received disability support before, I simply had no idea, to start with. When my first meeting was approaching, I knew that I would need to articulate my goals so I spent time talking to others about what those might be.”

“My first meeting was in person with an actual planner in the agency before the LAC system was introduced. It was fine.”

“My current plan is my best yet and I hope I can keep it this way. I have support funding for help around the home, social activities, etc. I have funding for upkeep of my guide dog and funding for orientation and mobility instruction from Guide Dogs. I have a budget for low-cost assistive technology, which I have used to purchase important updates for my screen reader. I also receive a contribution to disability related transport needs. In early plans I did not have the support worker funding that I could have benefited from and which has since opened up my life hugely.”

“It has been really great to have opportunities I never had before and not having to skimp and save for basic assistive tech.”

[*How has your NDIS plan helped you to become more involved in the community?*] “It has been amazing. I now get help to go to Parkrun for both fitness and health and an opportunity I could not have before. I can now have support to go to social events and programs that were too hard to go to before without support.”

Case study 11

Background:

- A teenage boy currently in Year 10, who lives in an inner-city suburb with his family.
- Lives with physical disability, intellectual disability, high levels of anxiety and is wheelchair dependent.
- Prior to accessing the NDIS, he was already receiving funded disability supports.
- He has been an NDIS participant for three years and is on his fourth plan.
- His mother contributed to this survey on his behalf; therefore, all quotes are written from her perspective.

“I had worked on goals with my son for many months and was very clear about what he needed. Had clear plans to give to planner.”

“My son loves going out with someone closer to his own age. He has age-appropriate fun with the support worker and feels that he has a friend.”

[*What has been really great about your NDIS experience?*] “My son has better equipment. The support worker is able to do personal care even on public holidays and weekends. Yay! Able to go out with a support worker fortnightly.”

Case study 12

Background:

- A woman who lives in a large regional town.
- Lives with psychosocial disability, which affects her in many areas of life and results in fluctuating functional impairment.
- She has been employed in the past but is currently not working.
- Prior to accessing the NDIS, she received some private psychiatric support but no disability funded supports.
- She has been an NDIS participant for four years and is on her fourth plan.
- She completed this survey independently.

“My son went to the office the first day they opened in the trial site to ask if I could join. My son helped fill out the form. It was obvious to everyone (but me) that the NDIS was necessary.”

“I didn’t know how to set a goal. I had lived up ’til then with no future so thinking about what I wanted wasn’t in my vocabulary. I had no sense of self. I just knew what I could not do. I didn’t understand how to articulate what my existence was like. But I drew and labelled a tree showing my life and obstacles. I was able to use that to talk to the NDIA and get a meaningful plan.”

“The most helpful thing has been self-managing as I can be innovative and hire people, not services.”

“I have discovered peers and peer movements through trying to be heard.”

[*What has been really great about your NDIS experience?*] “The sense of hope and excitement I felt at having a sustainable future. And my dog.”

Case study 13

Background:

- A man who lives in the outer suburbs of a capital city.
- Lives with physical disability from an acquired brain injury, which has resulted in impaired sight, mobility problems, cognitive difficulties and memory issues.
- He has been employed in the past as a sole trader but is currently not working.
- Prior to accessing the NDIS, he received support through state-funded programs and was also a recipient of a Disability Support Pension.
- He has been an NDIS participant for less than a year and is on his first plan.
- He completed this survey with assistance from his partner.

“I had assistance from my partner (who is my full-time carer) with the preparation for my planning meeting and also at the planning meeting.”

“I made a list of goals that I wished to achieve and I obtained reports from physiotherapists, occupational therapists, exercise physiologists and speech pathologists to justify my need for funding to pay for therapy so I could achieve my goals. It was tricky. I had to list all of the immediate goals – i.e., those that I could achieve within a year – and also list more long-term goals that I would need to work towards over a number of years. But I got a useful plan so it was worth it.”

[*What has been really great about your NDIS experience?*] “Getting intensive physiotherapy, personal training and OT – something I could have never afforded to do without NDIS.”

“It [the NDIS] has helped me to regain so much more mobility than I had before.”

Case study 14

Background:

- A man who lives in the outer suburbs of a capital city.
- Lives with physical disability from an acquired brain injury, which has resulted in severe fatigue, vision loss and cognitive deficits (memory, executive functioning, behavioural changes and vestibular issues).
- He has been employed in the past but is currently not working.
- Prior to accessing the NDIS, he received no funded disability supports.
- He has been an NDIS participant for less than a year and is on his first plan.
- He completed this survey with assistance from his wife.

“We met with the disability educator who helped us with the application and she helped us to prepare for the planning meeting. Without her help we would have been lost. It’s just a world that we are not used to navigating.”

“With the help of the disability educator we had come up with my goals before the planning meeting. She helped the process because it’s hard to plan ahead or look to the future.”

“We were very pleased with my plan and it was more than I hoped for.”

“I now have a support worker to transport me and assist me in the community without having to rely on my wife. This makes it easier to get out.”

“Getting money for hands-on support for me and my family has been epic. It helps the whole family unit.”

Case study 15

Background:

- A man who lives in the inner suburbs of a capital city.
- Lives with a physical disability resulting in wheelchair use, pain, fatigue and limited function.
- He has been employed in the past as a sole trader but is currently not working.
- Prior to accessing the NDIS, he received funded disability supports.
- He has been an NDIS participant for one year and is on his second plan.
- He completed this survey with assistance from his family.

“I had been using online groups and following others as they shared online, overwhelming documents from every org and their dog, but it did help me make a list of my life requirements.”

“[thinking about goals] was straight forward really. I had my list and had seen on the site the various things, just put the needs to the relevant sections and made brief statements as to reasons for each.”

“I had nowhere near enough care and had struggled for a decade under old state system, now I am drowning in care funding almost.”

“Mostly happy [with the NDIS] ... it is better having enough care to actually manage my life better now.”

Case study 16

Background:

- A young man who lives in a capital city.
- Lives with an acquired brain injury following an MVA.
- He currently works part-time.
- Prior to accessing the NDIS, he received a Disability Support Pension only.
- He has been an NDIS participant for one year and is on his second plan.
- He completed this survey independently.

“I have a support worker help me through one-on-one support, and therapists. I can do more stuff now.”

[*What has been really great about your NDIS experience?*] “Meeting someone to help when travelling, getting time apart from parents, and using assistive devices – all good!”

Case study 17

Background:

- A middle-aged man who lives in a large capital city.
- Lives with an acquired brain injury, which has resulted in issues relating to executive functioning, neuropathic pain, left-sided weakness and fatigue.
- He has been employed in the past but is currently not working.
- Prior to accessing the NDIS, he was already receiving funded disability supports and was a recipient of a Disability Support Pension.
- He has been an NDIS participant for one year and is now on his second plan.
- He completed this survey independently.

“I did a lot of planning for my plan meeting. Because of work done 10 months prior, I had a ‘life plan’ in place, which I had a copy of and handed to my LAC.”

“Luckily my plan has included support coordination.”

[*How NDIS has helped you to become more involved in community*] “Freedom to contract with support workers, thereby saving funds to put towards Comm, Soc & Rec, increased funding – these things have made a big difference to my life.”

“I have greater community access now as previously I was quite socially isolated.”

“I have better choice and control of who I engage in supports, I only engage ‘em if I respect ‘em!”

Case study 18

Background:

- A middle-aged woman who lives in a large capital city.
 - Lives with physical disability, which has resulted in mobility and speech impairment.
 - She is not currently seeking employment but would like to work.
 - Prior to accessing the NDIS, she was already receiving funded disability supports.
 - She has been an NDIS participant for less than one year and this is her first plan.
 - She completed this survey independently.
-

“I just worked out what I needed to live a ‘normal’ lifestyle.”

“I identified my goals using common sense! It was straightforward for me.”

“I think I have a good plan now to keep my body active. That’s the main thing.”

“You just have to be real about this system and find out how it can work for you.”

[*What has been really great about your NDIS experience?*] “How easy it is to get approval and ‘My Plan Manager’ organises my budgets... simple.”

Case study 19

Background:

- A young man who lives in the outer suburbs of a capital city.
 - Lives with an acquired brain injury, which results in short-term memory loss, social isolation and requiring assistance with some decision-making.
 - He works part-time.
 - Prior to accessing the NDIS, he was already receiving funded disability supports.
 - He has been an NDIS participant for less than one year and this is his first plan.
 - His parents assisted him to complete this survey.
-

“I planned for first meeting with parents’ help. I identified goals with parents’ help also with the help of organisation I already was with.”

“All supports on my plan are good.”

“The plan enables me to have lots more physio, which will help with my balance and flexibility. Also getting help with cooking skills and support with household cleaning.”

“The transport allowance is great as I am unable to drive.”

“Overall, NDIS is very good for me.”

Case study 20

Background:

- A young woman who lives in an inner-city suburb with family.
- Lives with an intellectual disability.
- She is currently seeking employment.
- She completed high school with 1:1 support in a mainstream public high school.
- Prior to accessing the NDIS, she was already receiving funded disability supports.
- She has been an NDIS participant for less than one year and this is her first plan.
- Her mother assisted her to complete this survey.

“My mother works in the disability field and was supported by colleagues to write an amazing plan that aims to provide me with a meaningful life in community.”

“I moved interstate to be with family and my mother manages the funds very well to provide me with my own support staff and a great introduction to life back with my family and in community.”

“It [the NDIS] has allowed me to move interstate to be with my family after 13 years of waiting on the [previous disability funding]. I can now go out on weekends and evenings. Where I was in [previous Australian state], I never went anywhere during these times; only stayed home with a worker and the two women I lived with.”

[*What has been really great about your NDIS experience?*] “Moving to [PLACE] to be with my mum and brother and using my own budget has been life changing.”

Case study 21

Background:

- A man who lives in the outer suburbs of a capital city.
- Lives with an acquired brain injury, which includes physical and cognitive disability.
- He was previously self-employed but is currently not working.
- Prior to accessing the NDIS, he was already receiving funded disability supports and was a recipient of a Disability Support Pension.
- He has been an NDIS participant for less than one year.
- His wife assisted him to complete this survey.

“My wife and I talked about my goals. My wife listed all of the goals I had and the supports I would need to attain those goals. My wife talked a lot to the people running the company we would use as our plan managers. This is where I got most of my information after the planning meeting.”

“Finally getting back my travel allowance allows me to attend lawn bowls and my volunteering at the church office, otherwise I would be socially isolated (as I was before I learned to drive a modified car, so I know how it could be).”

“We think we have found a provider now who we met this week and felt very comfortable with them. My support workers start next week. I am excited.”

Case study 22

Background:

- A middle-aged man who lives in the outer suburbs of a capital city.
- Lives with physical disability from spina bifida.
- He has been employed in the past but is now retired.
- Prior to accessing the NDIS, he received funded disability supports.
- He has been an NDIS participant for less than a year and is on his first plan.
- He completed this survey independently.

“I discussed my needs with my GP and my wife. It [the planning process] was straightforward for me.”

[How has the NDIS funding helped you to become more involved in your community?]

“I have felt able to offer my services to a boating committee.”

[What has been really great about your NDIS experience?] “Two new wheelchairs, one electric and one manual chair and assistance with gardening and house cleaning.”

Case study 23

Background:

- A high-school-aged girl who lives in an outer-city suburb with family.
- Lives with a physical disability, including mobility, balance and pain issues.
- She has had a part-time after-school job in the past.
- She completed high school with 1:1 support in a mainstream public high school.
- Prior to accessing the NDIS, she received no funded supports or pensions for disability.
- She has been an NDIS participant for less than one year and this is her first plan.
- Her grandmother assisted her to complete this survey.

“My meeting went very well with a very friendly, helpful lady. It was quite straightforward.”

“Having funds for physio, podiatry and special shoes have all been a big plus and helped a lot.”

[How has the NDIS funding helped you to become more involved in your community?]

“I joined a social activity with others in a similar situation.”

“So far, no negatives! I am just very thankful.”

“I have been able to get those services that make such a big difference, such as regular physio.”

Discussion

These case studies highlight that many participants are experiencing significant, positive outcomes through participation in the NDIS. These outcomes include new social connections, improved community participation, improved access to transport support and improved uptake of valued roles in the community.

JFA Purple Orange suggests that progress of the NDIS needs to be understood by measuring the outcomes achieved via any funded program or support mechanism. For instance, some of the outcomes of the scheme involve ensuring people living with disability access the core supports they need. These relate to material assistance, such as help with personal care, household support, transportation and the like. These benefits might be termed *transactional benefits* in that they are services that bring an immediate benefit.

Other outcomes involve assisting people living with disability to take up valued membership in mainstream community life, as students, workers, neighbours, team mates and so on. These benefits might be termed transformational benefits because they address the issues at the heart of the struggles reported by many Australians living with disability. Such struggles have been closely detailed within the *SHUT OUT* report from 2009.³

We firmly believe that transformational benefits should be the target outcome of the NDIS and any funded support scheme that aims to advance the lives of people living with disability. Our *Model of Citizenship* publication provides an example of a transformational benefit measurement tool.⁴

The following table provides examples of transformational benefits drawn from the case studies within this report.

3

Australian Government (2009), *SHUT OUT: The Experience of People with Disabilities and their Families in Australia*, National Disability Strategy Consultation Report prepared by the National People with Disabilities and Carer Council.

4

Williams, R. (2013), *Model of Citizenship Support: 2nd edition*, Julia Farr Association Inc., Unley, South Australia.

Example of a transformational benefit from survey data	How this benefit has led to valued membership in mainstream community life
"Finally getting back my travel allowance allows me to attend lawn bowls and my volunteering at the church office, otherwise I would be socially isolated (as I was before I learned to drive a modified car, so I know how it could be)."	Participant now reports involvement in lawn bowls and a volunteering role within a church.
(How has the NDIS funding helped you to become more involved in your community?) "I have felt able to offer my services to a boating committee."	Participant has now taken on a role within a boating committee.
"It (the NDIS) has allowed me to move interstate to be with my family after 13 years of waiting on the (previous disability funding). I can now go out on weekends and evenings. Where I was in (previous Australian state), I never went anywhere during these times; only stayed home with a worker and the two women I lived with."	Participant is reporting greater community participation.
(How NDIS has helped you to become more involved in community) "I am starting my own business, practising my literacy, building my communication skills, getting out in the community every day, joining groups of people who like doing the same things as me, practising photography, going to the pub, having parties at my house, and just generally starting to live independent of my parents."	Participant is now a business owner and is reporting greater community participation.
(How has your NDIS plan helped you to become more involved in the community?) "It has been amazing. I now get help to go to Parkrun for both fitness and health and an opportunity I could not have before. I can now have support to go to social events and programs that were too hard to go to before without support."	Participant can regularly be a member of their local Parkrun (a mainstream community event).
"My son has made amazing progress in two years from a child who would not leave the front fence without Mum to someone who goes on the bus home from community access day and also shops at the local stores on his own. He is making progress in life and being supported."	Participant can now access mainstream community services such as public transport and shops independently.
"My NDIS funding has helped me to be more involved in the community because I am able to get out of my house more often under the help of support workers; for example, trying ice-skating for the first time in my life! I am also able to get out of the house more to go visiting places that I like to go, and I have been able to learn to cook 3 recipes now (still with some support from Mom)."	Participant can access mainstream community activities such as ice-skating.

Table 1: Examples of transformational benefits drawn from case studies.

The above examples signal that for some people, participation in the scheme has led not only to recognisable benefits but to outcomes that are advancing them into greater life chances. What we mean by this is that the identified transformational benefits indicate the following outcomes:

1. They are outcomes that are supporting participants to build their capacity towards Citizenhood.
2. They are outcomes that are lifting participants' chances of having more people in their lives who are not paid to be there; e.g., they are relationships that are freely given.
3. They are outcomes that are providing participants with greater chances of the good things in life, such as being in employment, being in a safe and stable housing situation, having social connections with others and being a valued member in mainstream community life.

These case studies have demonstrated that, of our sample population of 94 NDIS participants, nearly a quarter (24.5%) are benefiting significantly from NDIS participation. The 23 case studies highlight NDIS participants having significant increases in life chances and, in some cases, genuine 'transformational benefits'. This finding is hugely encouraging for the capacity of the scheme to advance participants into lives characterised by greater community, economic and social participation and increased ability to build their capacity for Citizenhood.

Implications for practice

JFA Purple Orange asserts that the main impact of providing participants with plans that assist them to receive significant benefits and outcomes is that the scheme is then supporting people to grow capacity.

Using social role valorization (SRV) methodology to understand beneficial NDIS outcomes

Wolfensberger and colleagues conceived the concept of SRV in the 1980s, based on the premise that some personal characteristics and qualities are valued more highly than others.⁵

The roles that people have are often valued differently, too. People hold a variety of roles, such as work roles (e.g., teacher), relationship roles (e.g., mother), civic or community roles (e.g., tax payer) and leisure or recreational roles (e.g., football supporter). Generally, people can gather many roles randomly over the course of their life without the need for much effort in deliberately seeking these out. That is, these roles naturally evolve through activities and relationships people have in their lives. Many of the roles people have are valued because they are associated with features such as wealth, competence and independence.

However, people living with disability typically have fewer roles, or fewer roles that have positive value. For instance, people living with disability might have the role of patient or pensioner, and these are roles that our society does not especially value. These roles are also often linked to dependence and poverty. People without valued roles will find it harder to access those things that society calls the 'good things in life', such as a home, meaningful work, and opportunities to meet people and form relationships. Put simply, valued roles open the door to new possibilities and opportunities.

The case studies presented in this research report highlight the ways in which the participants are moving into valued roles in society as a result of their NDIS participation. The roles identified include volunteer roles, community roles and strengthened family roles. These roles have assisted these participants to access more of the 'good things in life', with several examples showing greater opportunities for meeting people and forming relationships.

5 Wolfensberger, W. (1985). "Social role valorization: A new insight, a new term, for normalization." *Australian Association for the Mentally Retarded Journal*, 9(1): 4–11.

Elements that lead to a beneficial pathway

Through the previous work that our agency has done regarding the implementation of the NDIS, we feel heavily connected to people who are participants of the scheme and people who are supporting participants of the scheme. We recognise that the NDIA has announced the systematic rollout of updated arrangements to the NDIS participant pathway, and that these arrangements are likely to lead participants to improved planning experiences and, as a result, improved plan content, goals and outcomes.

From previous research work, there are some factors that JFA Purple Orange has seen that we believe are what lead to a pathway that will deliver participants beneficial outcomes, or, more particularly, transformational benefits. The elements that we see as being most pertinent towards these outcomes are:

1. Providing participants with an individualised budget, so that they can purchase the things that will advance them.
2. Designing a participant pathway that is focused on choice and control; the values that are the central anchor points of the scheme.
3. Providing participants with a plan that has adequate tailored support such that people can have enough flexibility to buy the supports that will genuinely advance them.

JFA Purple Orange would like to emphasise the importance of the planning process in regards to successful NDIS participation outcomes. Many of the case studies presented in this report mentioned successful planning meetings, for which participants were well supported and well prepared. We feel that if there is to be a genuine shift in the centre of gravity of the scheme towards transformational benefits, then the planning processes must reflect this. This speaks to the way in which staff who are acting on behalf of the NDIA during planning processes, such as the LACs and the planners, are approaching their roles. For example, it is necessary for these staff to receive guidance and support towards their practice as essentially their role is to be there alongside each participant, crafting how this scheme is going to respond and help the person to genuinely advance their life.

Conclusion

This report has demonstrated the ways in which participants are achieving successful outcomes from the NDIS. Some of these benefits are *transformational benefits*, meaning they are bringing transformation into the person's life. This is variously in terms of self-belief, knowledge and skills, using mainstream amenities, social connectedness. In particular, many of the benefits identified in this study have assisted NDIS participants to take up valued roles in their mainstream local community.

JFA Purple Orange asserts it is imperative for NDIS participants to be supported to build NDIS plans that bring transformational benefits. Reports that identify and promote real life positive outcomes from NDIS participation are critical for assisting NDIS participants to imagine an ordinary valued life and to move towards it.

As such, a sustained focus on stories of genuine transformational benefits is critical to the long-term success of the NDIS.

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