



DSA NDIS Survey 2018



Demographics

What do we know about the respondents?



Survey respondents

- 396 people responded to the survey
- 95% were family members (85% of those being parents)
- Majority were female.
- The people with Down syndrome they represent were split 56% male and 44% female.
- Respondents were from every state and territory. The geographic split was relatively representative of the population.

Background of respondents

- 57% of respondents were from metropolitan areas, 38% from regional areas and 4% from remote or very remote areas.
- 2% identified as Aboriginal or Torres Strait Islander.
- 7% were from a CALD background.
- Age range of the person with Down syndrome was 0-65 with the majority aged 30 or under (87%).
- 92% lived in an area where the NDIS has rolled out (only these went on to answer the remaining questions).



Access experiences

What was the access process like for respondents?



Access

- 52% had to get specialist reports to get access to the NDIS. 24% already had the necessary reports, and 21% had automatic eligibility.
- Many people had to pay for specialist reports with costs ranging from \$100-\$1500. Some people we are able to get reports through other sources of disability funding (Better Start etc.) or bulk-billed services.
- Only four people reported that they were denied access to NDIS but these decisions were overturned on review.
- People noted having to access specialists that they had not previously seen (e.g. psychologists) due to the proof required for access.

Access experiences

- *“The level of information required was so much more than expected, and the volume of reports was staggering. My son has multiple disabilities so needed to provide proof of each of these.”*
- *“NDIA gave very short deadlines to obtain documentation and some of our therapy providers struggled to meet these. When asked what would happen if these reports were late, the NDIA bluntly stated ‘you will not meet access requirements.’”*
- *“The whole experience was very time consuming and stressful.”*
- *“We originally provided our own 'evidence' (Dr's letter confirming DS diagnosis and speech report), from that we were denied access. We then had our OT fill out the NDIS access form and were then approved.”*

Cont.

- *“I felt demoralised and disempowered having to provide proof that my daughter has Down syndrome.”*
- *“I didn’t understand why I had to prove my daughter’s IQ or how she needed support. This should have been understood once I provided evidence of her diagnosis. It reinforces a deficit model and is very traumatic to families. Why doesn’t the NDIA know that people with Down syndrome need support? It is not that complicated.”*
- *“It took me a while to get access to the NDIS. Living in a regional area, access to specialists is limited. It can take a while on waiting lists before you can get to see the person who needs to write the report. It just felt unfair. Wasn’t it enough to show that she has Down syndrome?”*

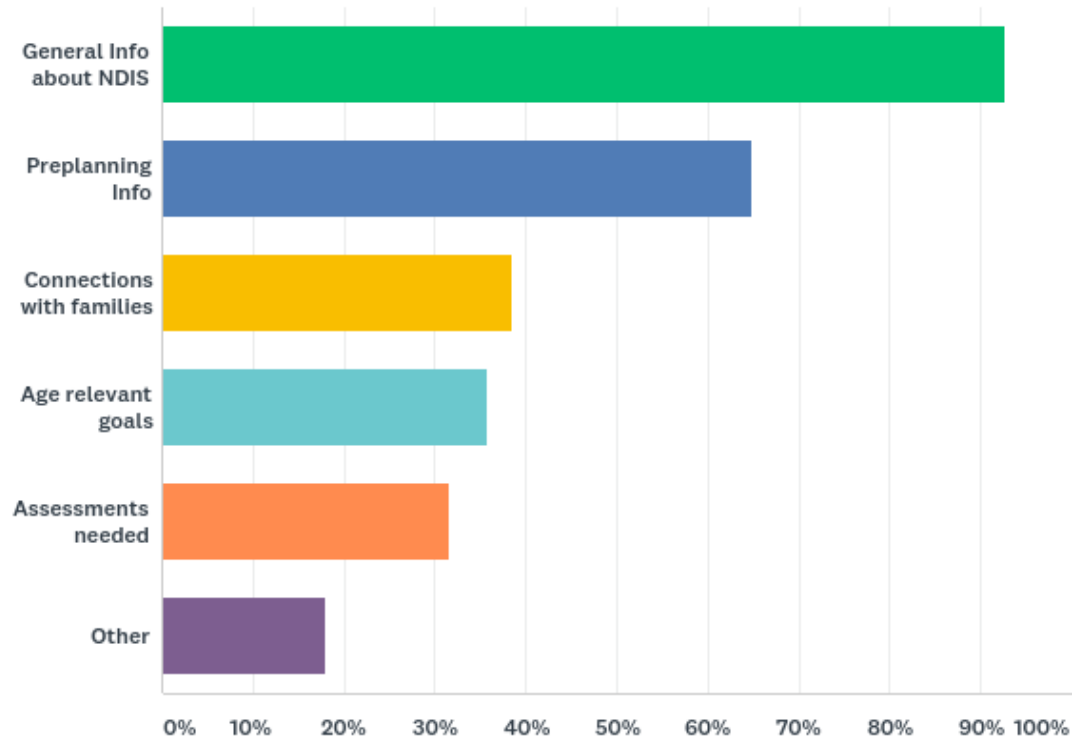


Planning experiences

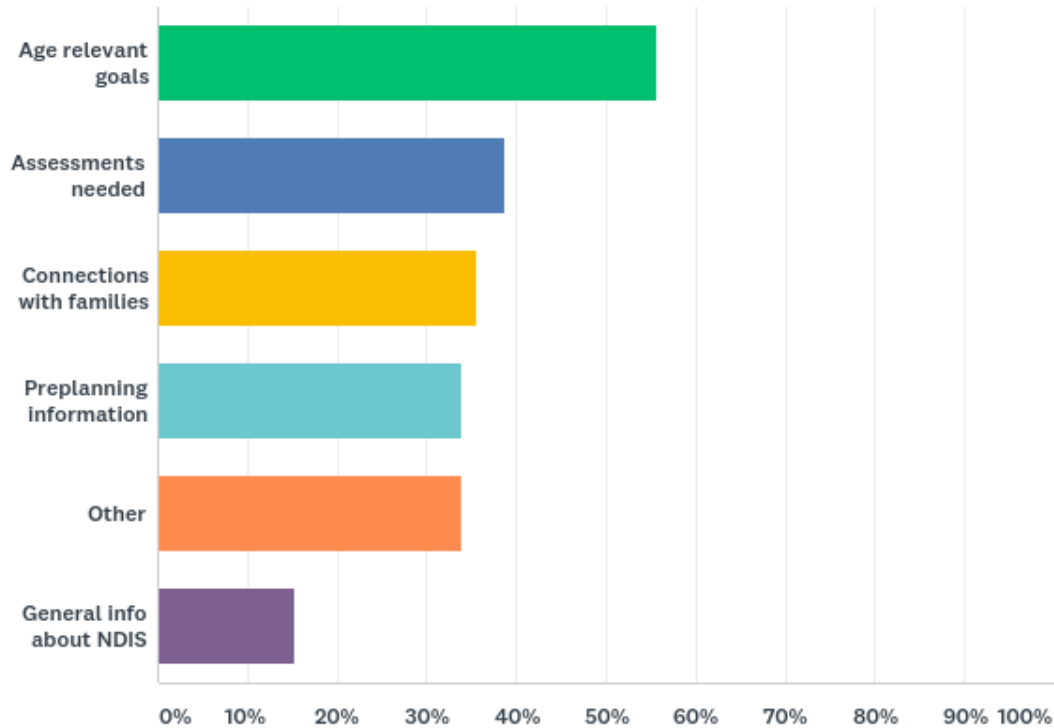
What was the planning process like for respondents?



Q26 What information did you have before the planning meeting?



Q27 What information did you wish you had before the meeting?

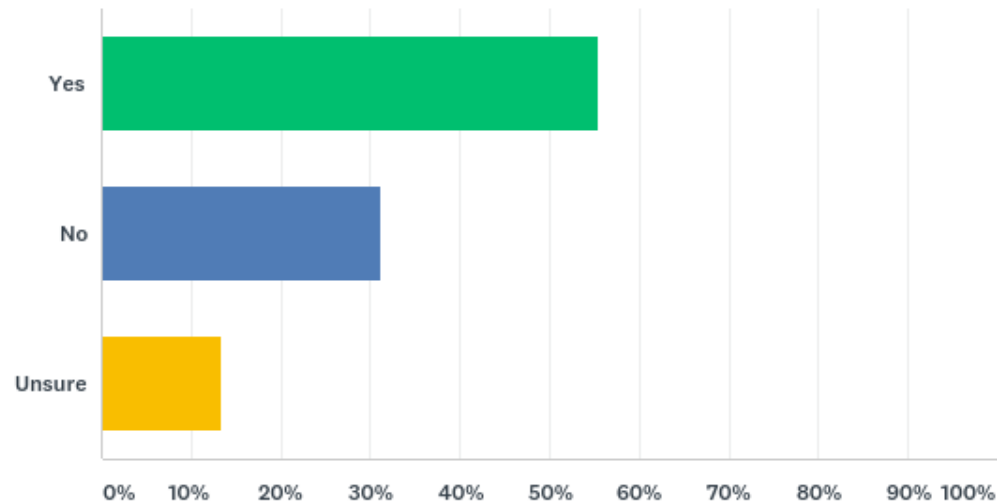


Planning meeting experiences

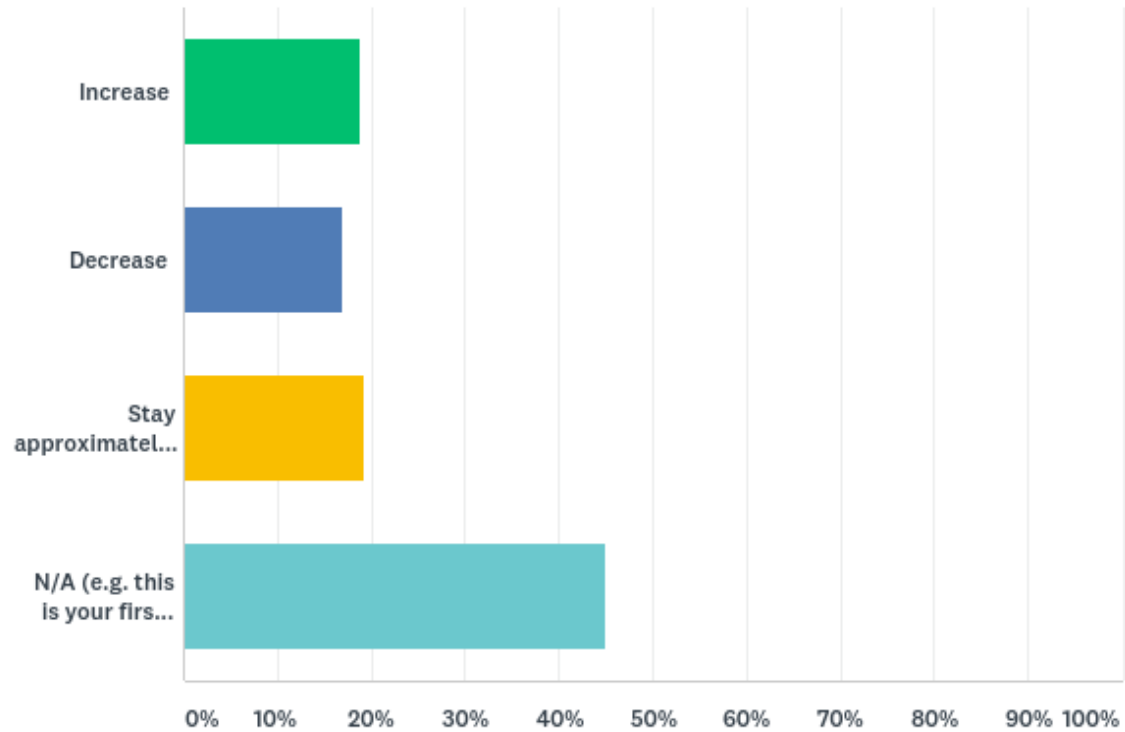
- NDIA representative's understanding of Down syndrome
 - *49% said poor/fair*
 - *23% said very good/excellent*
- NDIA representative's communication with you and the person with Down syndrome
 - *31% said poor/fair*
 - *23% said very good/excellent*
- The discussion of goals with you and the person with Down syndrome
 - *38% said poor/fair*
 - *38% said very good/excellent*
- The overall experience of the planning meeting
 - *36% said poor/fair*
 - *38% said very good/excellent*

Planning experiences

Q36 Are you happy with the plan you received?



Q37 Compared to your previous plan did funding?



Self Managed vs NDIA Managed

- Satisfaction with plan received
 - *48% of NDIA managed were satisfied*
 - *61% of self-managed were satisfied*
- Is this how you wanted to manage the funding?
 - *71% of NDIA Managed said yes*
 - *99% of Self Managed said yes*
- Are you having any difficulty with this way of managing your funding?
 - *41% of NDIA Managed said Yes*
 - *22% of self-Managed said yes*
- Have you been able to get the supports you need to implement the plan?
 - *66% of NDIA Managed said Yes*
 - *77% of Self-Managed said Yes*

Planning experiences

A number of themes emerged from free responses about the planning experience including:

Lack of understanding of Down syndrome

- *“The LAC did not appear to understand the issues of a person with DS, considered her abilities to be in ‘normal’ range despite having poor to no communication skills, and did not understand that she needed support in all areas (supported employment, day options, mental health issues preclude safe at home alone). LAC seemed to think that it was normal for a parent to be unable to work. Compared the needs for support for my young adult with DS to her Year 12 student son with mild Dyslexia.”*

Cont.

- *“Our representative had no knowledge of Down syndrome and we had to push her to lodge for a NDIS package as she wanted to just access free therapies like kindergym and playgroups saying we needed to wait and see how our daughter would keep up with peers. As a parent new to the NDIS system and new to Down syndrome I struggled to know what goals or what therapists she would need.”*
- *“They knew nothing of the complexities nor do they understand about intellectual disability and how difficult it can be for our kids to learn toileting and safety for example. It's the most stressful thing I have encountered.”*

Planning experiences

Incorrect information about what services can be included or being pushed to use segregated services

- *“Planner told me early onset Dementia would not be eligible for funding, I knew it was after attending your training sessions. Tried to suggest it was – planner wouldn’t have a bar of it. Went into NDIA office to express concern they said it would be included. Wouldn’t listen to our concerns regarding DHHS. Explained there was no capacity for extra curricular activities in house due to extreme behaviours of concern & complex disability. Said this should all be provided at present, it’s not”*

Cont.

- *“NDIS rep tried to encourage us to move our daughter from Project Independence, a semi independent living home in ACT, to ACT government shared housing despite our commitment to her staying in PI primarily so she would have the security of owning her own property in the future. It was suggested it would be easier for her to access services if she lived in shared housing with others as they can all be collected together for activities despite her having lived in her accommodation for 12 months and absolutely loving it.”*

Planning experiences

Positive experiences when the LAC had good understanding of Down syndrome

- *“The planner was a paediatric physiotherapist so understand needs well”*
- *“The better prepared you are the better. Pre-planning essential. The Brotherhood of St Laurence staff are professional, well trained, respectful and empathetic.”*
- *“My representative had a background in Occupational Therapy so I feel she has a greater understanding of disabilities and also goals and equipment. She’s lovely and easy to talk to.”*
- *“A great deal of empathy and willingness to assist in achieving an appropriate outcome.”*

Example goals (ages 0-7)

- communication skills (including key sign)
- assistance with daily living skills
- behaviour management
- toilet training
- regulation of emotions
- development of motor skills
- safe movement in the environment
- improved mobility
- improved regulation of sensory needs
- independence in self care (feeding, dressing)
- school readiness.

Example goals (ages 8-15)

- communication skills
- assistance with daily living skills (including development of motor skills, managing money, using public transport, personal hygiene)
- independence in self care (feeding, dressing)
- developing relationships/friendships
- learn how to ride a bike
- behaviour management
- support to access community activities (sporting groups)
- toilet training
- physical fitness
- regulation of emotions
- mobility
- strategies to deal with transition to high school

Example goals (ages 16-18)

- communication skills
- social participation (including sports, dance groups, social clubs)
- work experiences/support to transition to work/volunteer experiences
- managing emotions
- independent living skills (including money management, use of public transport/taxis, cooking, hygiene)
- learn to ride a bike

Example goals (ages 19-30)

- communication skills
- improve literacy
- social participation (including sports, dance groups, social clubs)
- work experiences/support to transition to work/volunteer experiences/open employment/ job satisfaction
- managing emotions
- maintain/establish independent living
- independent living skills (including money management, use of public transport/taxis, road safety, cooking, hygiene)
- improve fitness/healthy lifestyle
- learn to ride a bike
- attend programs and recreational activities
- behaviour management
- supports to enable parents to continue in their caring role

Example goals (ages 31-55)

- communication skills
- support team to receive training in participant's language
- support and equipment to be more independent
- improve mobility
- social participation (including sports, dance groups, social clubs, computer studies, art, photography)
- continued support for employment, supports to assist transition to open employment
- develop skills to go on holidays independently

Cont.

- managing emotions/behaviour
- maintain/establish independent living
- develop independent living skills (including money management, use of public transport/taxis, road safety, cooking, hygiene, doing the shopping)
- live in supported accommodation of my choosing
- improve fitness/healthy lifestyle
- attend programs and recreational activities
- supports to enable parents to continue in their caring role

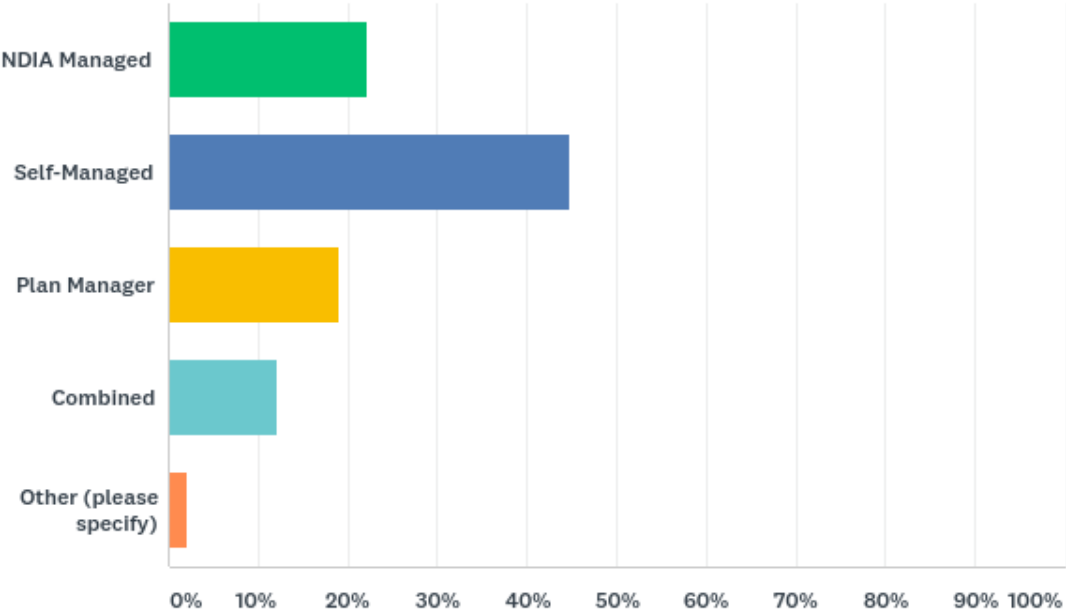


Plan Implementation

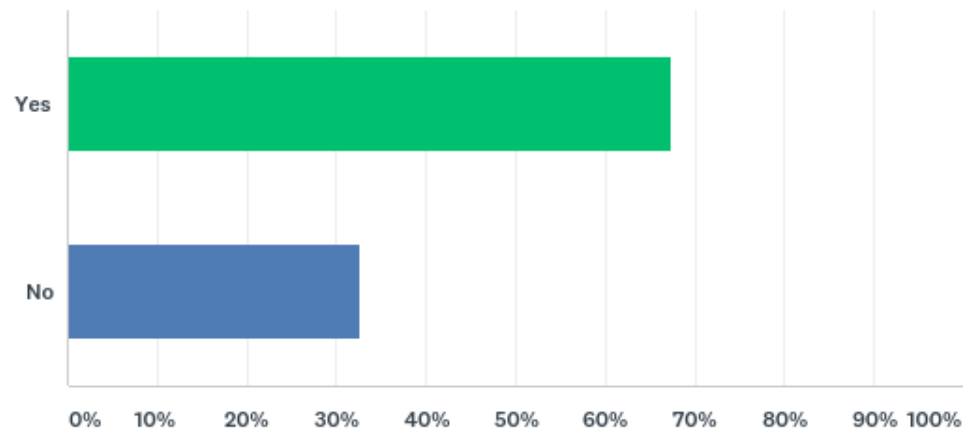
What happened after the plan was received?



Q46 How are you or the person with Down syndrome currently managing or planning to manage their funding?



Q49 Have you been able to find and get the supports the person with Down syndrome needs to successfully implement the plan?



Implementation experiences

Biggest barriers to getting support:

- difficulty finding the right support workers (38%)
- lack of services available (37%)
- difficulty finding the right provider (35%)
- time involved in providing support to attend therapies (30%)
- insufficient funding (27%)
- transport to services (23%)
- needing more time to adjust to changes to routine/new therapies (23%)

Another barrier to plan implementation is understanding of NDIS, with a third of families reporting their understanding of NDIS was poor or fair.

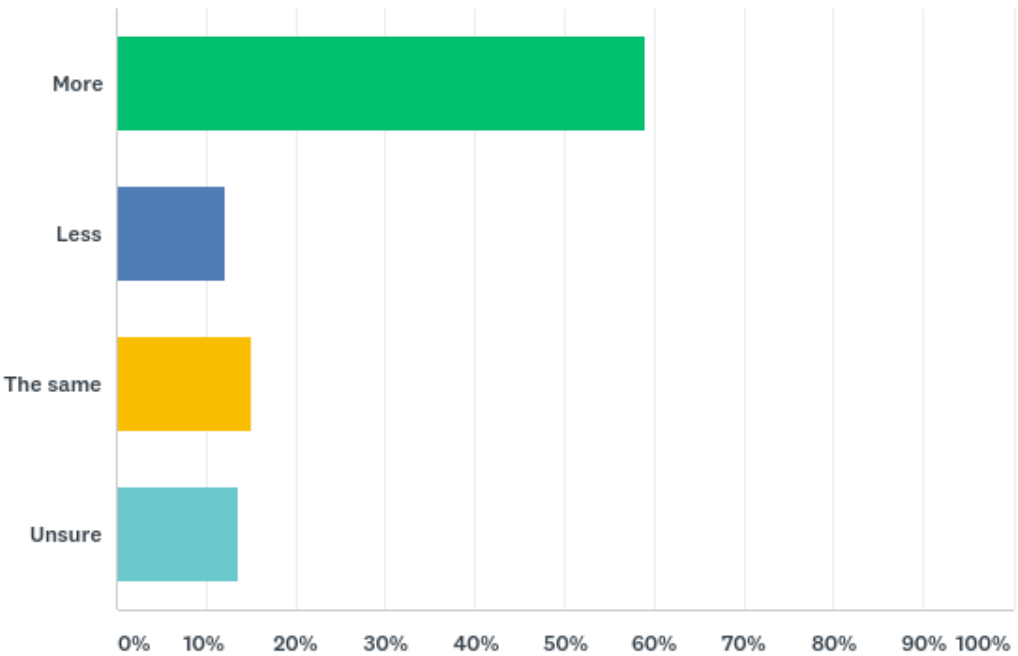
Examples of barriers

- *“I literally spend hours talking to people trying to get things moving for my son to no effect. For example my son had 15 hours funded for an OT. So far 13 hours have been used up on the initial meeting, her report and emails and phone calls. Nothing has been done to help my son with the cooking or travel training this funding was intended for. Now the OT tells me that she needs the last two hours to write her report. Arrghhh. I see NDIS funds being spent on lots of people who can talk to me but very little assistance makes it to my son.”*

Cont.

- *“My son had funding for a temperature controlled tap which would allow him to shower independently. After waiting 10 months for the approval I paid the \$1000 to have it installed. My pleas to have this done fell on deaf ears even though the funding was there. If my son didn't have me to advocate for him he would be completely and utterly overlooked. Getting a plan approved means absolutely nothing if you can't actually get the dollars to work for the person with the disability.”*

Q51 Is the support the person with Down syndrome is receiving under NDIS more or less than the support they received before becoming an NDIS participant?



Impact of NDIS

Developing friendships with people outside of the home

- 43% said it had been somewhat, very or extremely helpful

Supporting education and learning

- 51% said it had been somewhat, very or extremely helpful

Helping to get involved in community groups

- 31% said it had been somewhat, very or extremely helpful

Employment

- 16% said it had been somewhat, very or extremely helpful

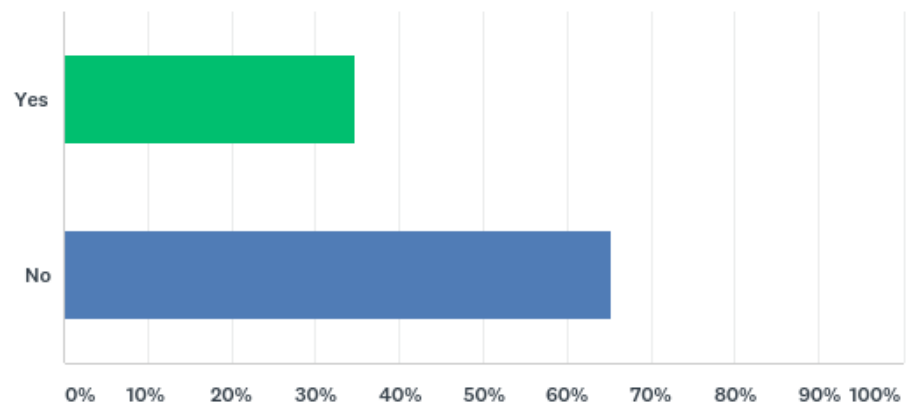
Independence

- 55% said it had been somewhat, very or extremely helpful

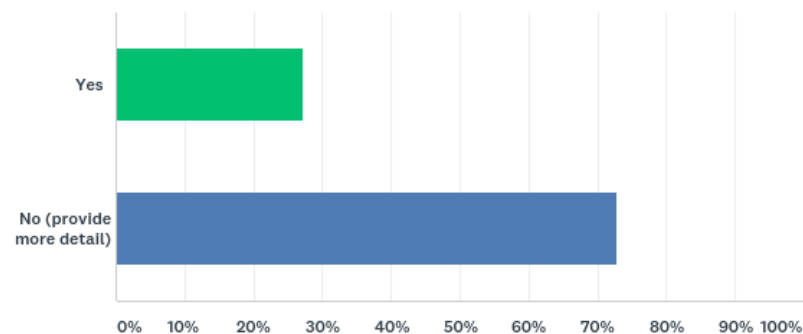
Wellbeing

- 56% said it had been somewhat, very or extremely helpful

Q56 Have you asked for an unscheduled review because you were unhappy with your plan?



Q57 Were you satisfied with the outcome of this review?



Advice for other families

Themes that emerged from free response:

- make sure you have good information
- be a strong advocate - ask for a review if plan is not adequate
- be prepared - and to bring lots of evidence of need
- get support - bring along a family member or friend
- get support from your peers (NDIS and me and other Facebook groups)
- think outside of the box - what might be possible, not just more of the same
- emphasise community participation and involvement in mainstream activities
- make sure you request specific equipment in the planning meeting (if needed)
- be careful not to get caught up in negative stories - they are the exception rather than the norm
- make sure planner is aware of the interaction with other disabilities



Summary

What does this survey tell us?



Summary

- NDIS has been a positive change for most people with Down syndrome, with most people getting access to more support than they have had before. It has had positive impacts on independence, wellness, employment and education.
- There are some significant challenges and barriers for how people interact with the NDIA. This includes the access process, knowledge of planners, issues around implementing plans and understanding of the NDIA.
- People want more information on how to get ready to enter NDIS including understanding what relevant goals might look like, what evidence is required and what they should expect.

Cont

- People want more support and better IT systems to support self-management of plans.
- Families value having access to peer support and getting advice from other families who have already gone through the planning process.
- Participants want greater consistency, staff who understand Down syndrome, and a more appropriate process for access to the scheme.