

*family*

A D V O C A C Y

# Submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) into the Transitional Arrangements for the NDIS



Family Advocacy  
Systemic Advocacy Team  
July 2017

# Contents

Executive Summary	1
Family Advocacy	3
A. Boundaries and interface between NDIS services and mainstream services	4
- The need for advocacy	4
- Mainstream service - Health	5
- Issues with peg feeding - HEN	6
- Mainstream service - Education	8
B. The consistency of NDIS plans and delivery of NDIS services	10
- A recent survey from our families	10
- Planning meetings need to be documented	11
- Inaccessible: participant's relationship with planners	12
- Plans in plain English	13
- Supports before and after	14
- Majority of participants unhappy with plan	15
- Large gap between support needs and the plan - planner unprepared or portal problem?	16
- Increase in review/appeal numbers due to poor planning process	18
- Reviews have long and unreliable timeframes	19
- Minor amendments to plans without triggering a full plan review	20
C. Any other related matters	21
- Self-management supported by the NDIA	21
- Investing in Local Area Coordinators and Planners	22
- More flexibility is required for payments to unregistered providers	23
- Support self-direction: support coordination	24
Conclusion	24

# Executive Summary

This submission is based on a survey of 100 family members of participants in the National Disability Insurance Scheme (NDIS). It is also shaped by the accumulated knowledge of families over 25 years of advocating for supports, policies and practices that value the lives of people with disability, as well as Family Advocacy's experiences in supporting families as the NDIS rolls out.

Family Advocacy has made the following key points:

## **A. Boundaries and interface of NDIS and mainstream services**

- a. Advocacy should continue to be funded at combined State and Federal levels
- b. Clarity is required regarding the interface between the NDIS and mainstream services, especially boundaries at the operational level around the supply of services to people with a disability
- c. The NSW state government should only withdraw services when continuity of service is guaranteed by the NDIS
- d. The NDIS needs to be actively engaged in discussion and reporting on the interface with mainstream services around the service gaps, duplications and boundary issues through the relevant COAG Councils
- e. We recommend guidelines for access to therapies in school hours be produced between the NDIA and state education departments, so that some clarity and recourse is available when and if there are extenuating circumstances or the guidelines are not being followed.

## **B. The consistency of NDIS plans and delivery of NDIS**

- a. Participants or their nominees need to see a draft plan to avoid unnecessary reviews and to alleviate any anomalies or misunderstandings
- b. Participants need to meet their planner face to face, and have contact details for their planner and Local Area Coordinator (LAC)
- c. Plans should be written in plain English
- d. There is a need for Participants to have support in the pre planning process to ensure their situation and goals are understood
- e. Participant's need support to navigate the plan, once it is issued
- f. Also, a much deeper understanding of what makes for an ordinary life for a person with a disability is needed. Family Advocacy would be happy to discuss resources and training for LACs and planners
- g. The National Disability Insurance Agency should report consistently in relation to



# Executive Summary

- the number of Internal Reviews, nationally and in each State, and reveal it publicly, in the interests of transparency to participants and the public
- h. Minor changes to plans should be possible without the need for a full review.

## **C. Any other related matters**

- a. Self management must be understood and supported by NDIA staff, LACs and planners
- b. This change in practice must also be coupled with more in depth training of LACs, and planners, to understand what self management can look like and how it can work in a participants life
- c. Levels of NDIA registration for providers should be based on risk. This may facilitate the emergence of small boutique groups that provide supports to those participants and nominees who wish to self direct
- d. The Agency should develop a pro forma checklist of options for management of the plan with examples, which could be worked through in each initial meeting and at the 12 month review stage
- e. More flexibility is required so that plan-managed participants are not entirely bound by the price guide. We believe there needs to be more flexibility and greater inclusion for more informal supports to allow for true choice and control.
- f. Greater flexibility is required in the system with the use of support coordinators throughout the duration of a participant's plan
- g. We recommend that Support Coordinators be more accessible to each participant.

# Family Advocacy

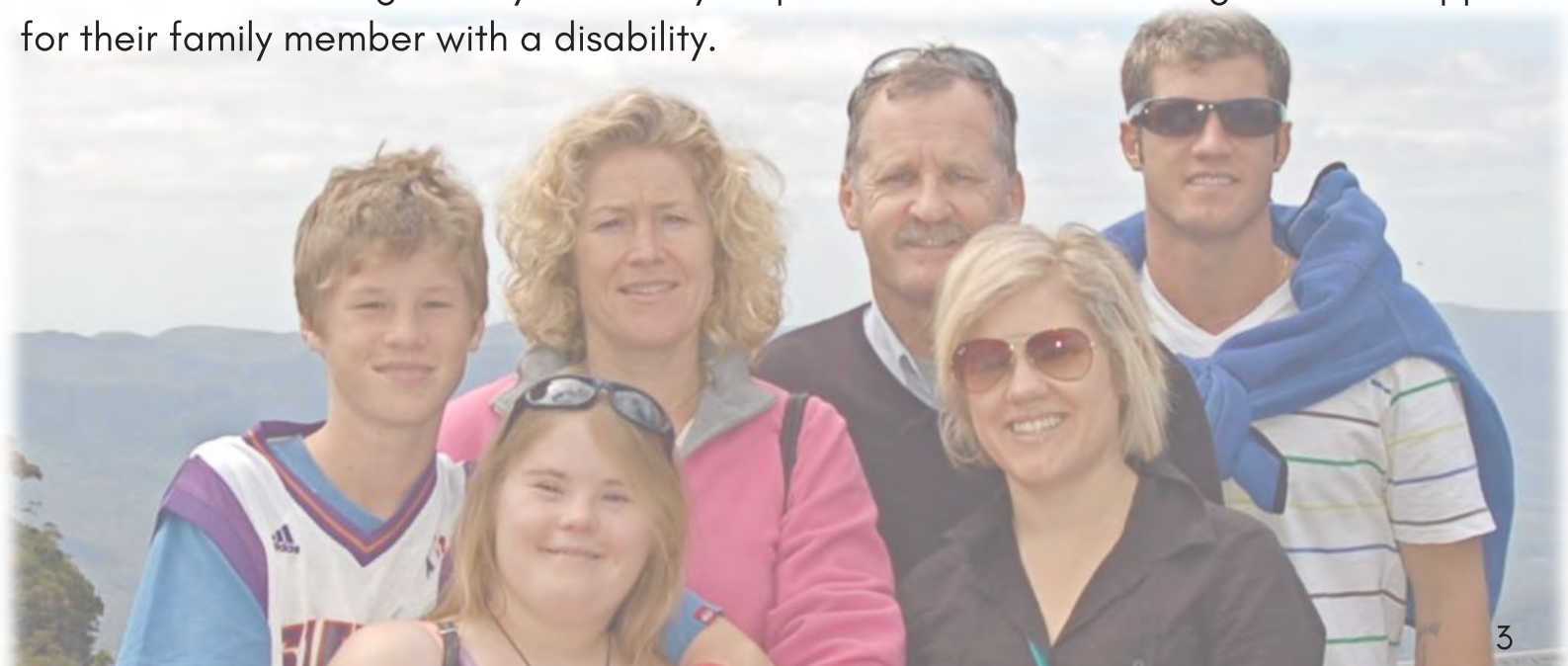
*family*

A D V O C A C Y

Family Advocacy empowers families to advocate on behalf of their family member with disability. We support families to advocate for a good life with the things most of us would expect in Australia: a place to call home, a valued place in the community amongst friends and family, and the supports, informal and paid, necessary to make that happen.

Family Advocacy was founded by families of people with disability and is funded by New South Wales (NSW) and the Commonwealth. Our purview lies in alignment with the overall objectives and aims of the National Disability Insurance Scheme Act (1 July 2013). Our goal is to advance and protect the rights of people with developmental disability to achieve meaningful lives and enjoy the same opportunities and living conditions as the majority of Australians.

One of our initiatives, Resourcing Families, was designed to inform and resource families to support their family member with disability to live a meaningful and typical life as a valued member of their community. Resourcing Families aims to assist families to develop their capacity and confidence to have more choice and control over decisions and support arrangements that will facilitate individualised lifestyles for their family member with a disability around their genuine interests and aspirations. This includes making the most of emerging opportunities for self directing supports through individualised funding. Family Advocacy empowers families to make good lives happen for their family member with a disability.



# A. Interface between NDIS service and mainstream services

## **The need for advocacy**

A necessary go-between all of the boundaries and the interface between the NDIS and mainstream services is advocacy. Our families have expressed shock that so much advocacy is required on their part under the new system. They want to be heard and see the system improve, but are frustrated and do not know where to turn. Many individuals with an intellectual disability, and their families, do not have the energy, time, advocacy skills, computer literacy, language skills and/or confidence required to self-advocate. No system is perfect and disability advocacy organisations such as ours provide an alarm bell to warn where there are systemic barriers in order that the NDIA can respond to failures in the system and prevent unnecessary cost and time wasting. For these reasons, advocacy must continue to be provided so our most vulnerable people with disability continue to have a voice.

Ironically, the New South Wales government has announced that it will cease advocacy funding after June 2018 – when it is needed the most in the midst of a new system. A person with a disability should not have to pay for advocacy services out of their own pocket or plan as they are already vulnerable and subject to an imbalance of power in society. Advocacy support should continue to exist for all people with a disability at no cost to them. Further, they should not be excluded from having a voice due to their being no one to turn to for advocacy.

To address this, we recommend that advocacy should continue to be funded at combined state and federal levels. We commend the federal government for recently extending advocacy funding to the tune of \$60 million until June, 2020. We ask that the Joint Standing Committee recommend the federal government continue to call on the New South Wales government to do the right thing and meet their commitments to people with disability by committing to ongoing support for advocacy under the NDIS.

## Mainstream service - Health

Mainstream services should be available to all people, including people with disability. There are a number of concerns our families raise in relation to the interface between the NDIS and mainstream services and supports. People with disability and their families have borne the brunt of the lack of transparency and lack of clarity in the governance arrangements. Some disability supports are being cancelled because of unclear boundaries about the responsibilities of the different levels of government.

Graham, father of Craig, says:

We have not even been booked for our planning meeting yet but some of our activities have been cancelled pending NDIS funding, very upsetting for the intellectually disabled.

Dorothy, mother of Maree, says:

Made complaints with FACS and DSS for not transferring services. Engaged advocate as we had existing services cancelled. Partially funded only 70 of the 150 hours in home care, now waiting for review. I feel insulted by NDIS referring us to Department of Education in-home care, which only funds 13 weeks and is for kids at risk and parent needs to be at home. Hardly appropriate when services are required for 1.5 hours so parents can get home from work. Mainstream after school care refuse services due to toileting policies and procedures. Not a good experience. NDIS is not person centred. They are not trying to help families and instead trying to fob them off to other government departments to pay for services. Really not happy and extremely stressful time in our lives and still not resolved almost 7 months later.

## Issues with peg feeding – HEN

Another example of issues families are having with the interface of NDIS and the Department of Health is in attempting to navigate Home Enteral Nutrition (HEN) service. In case you are unfamiliar, HEN is the provision of nutrition support therapy by mouth or by feeding tube into the gastrointestinal tract, for children or adults that cannot eat safely or adequately to meet their nutritional needs, in the home setting. This can be short term or continue indefinitely.

In one case, the planner stated that she was informed a ruling had been made that HEN's services and consumables will be the responsibility of Health and not that of the NDIS. However, another family then informed her of a recent plan which included HEN consumables and nutritional supplements. Following a discussion with the nurse at the hospital to confirm this was the case, the family from the planning meeting had a subsequent conversation with the planner, who was trying to get HEN consumables and nutritional supplements included in the plan. This is very confusing for families in what is already a tumultuous time of change.

In another case, Darren just turned 18 and is transitioning into the adult health system. Prior to NDIS, EnableNSW covered the costs of consumables, enteral foods and nutritional supplements. These were funded for 80% of his annual allocation as the total cost of consumables was greater than \$800. In his NDIS plan, he was allocated \$2282 funding in Improved Health and Wellbeing for Dietitian Consultant and diet plan development, there is funding under Core for 'Hen Pump and associated consumables (non-syringe feed)- annual'. There is no funding identified for enteral food or nutritional Supplements. Previously, EnableNSW provided funding to support Darren's yearly allocation above the \$800 threshold. His family are unable to sustain these additional costs and have had to go without personal supports and capacity building opportunities in order to sustain existence. Darren and his family are confused. Families were not supposed to be worse off under NDIS.



Several families have been put in untenable situations when trying to purchase vital enteral food products nutritional supplements:

- Families are not being properly educated on the processes involved in accessing affordable enteral food products and nutritional supplements
- The processes involve in accessing NDIS contract prices are not clearly explained and when explanations are given there are inconsistencies
- Companies have confused families with inconsistent service processes. They are concerned that they are not being informed of the reduced contract prices and charge higher rates
- Families feel inadequate and anxious as they cannot get consistent information. They ring NDIS on four different occasions and they get four completely different answers
- Information from NDIS & Consumable Sales Companies is frequently inconsistent with information from the HEN Dietitian Coordinator
- There is confusion over who is an eligible prescriber in order for families to get the discounted contract price from companies. Dietician from Department of Health NSW or private practice dietitian. Referrals from private practice dietitians are being refused.
- Participant's and families feel they are wasting their support coordination funding trying to find out if Department of Health or NDIS are going to take responsibility.
- In one instance, a parent was on the phone crying and distraught with no food to feed their child. Another family had a planner that did not know what a peg feed was, the participant had to explain.

These are individuals and families with very complex lives and they require clear and concise information:

- In the form of a detailed document
- Which government department is responsible to funding HEN
- Transparent explanation as to how individual variable needs are funded
- How to access contract pricing & who provides this
- Who can refer/eligible prescribers for contract pricing
- Appropriate circumstances for PBS scripted HEN
- Equipment, products, clinical criteria, annual allocation, higher supply

The right to food is a basic human right. People who eat via a tube face additional barriers. It is imperative that an equitable and consistent program for access to HEN exists to enable all participants to maintain their health and quality of life at home, and reduce hospital admissions. If this does not occur, participants and their families are disadvantaged not only by cost, but also by the time needed to negotiate the system. This is valuable time in the context of dealing with complex health needs with many other pressures on participants and their families.

Accordingly, we recommend that the Commonwealth and the State governments must set clearer boundaries at the operational level around the supply of services to people with disability, and only withdraw when continuity of service is assured. There needs to be discussion and reporting on the interface with mainstream services and the NDIS around service gaps, duplications and boundary issues through the relevant COAG Councils.

## **Mainstream service - Education**

A number of issues have come to our attention regarding the interface between education and the NDIS, including the Assisted School Travel Program and access to NDIS funded assistance at school.

### Assisted School Travel Program

It has come to our attention that some families have been denied funding from the NDIS for items such as car modifications due in part to the availability of the Assisted School Travel Program, which runs around 3000 travel services daily for approximately 10 500 people. Unfortunately, this program does not live up to the promise of the NDIS regarding ordinary lives in the community, as it is specific to children with disabilities, and automatically grants eligibility to students attending special schools or support classes. In its specificity, it adds to the segregation of students with disability from their non-disabled peers.

In relation to the interface, it is concerning that other, more ordinary options such as a car modification which would enable a typical family school drop-off, are being denied in favour of a congregate service. Additionally, the Assisted School Travel Program eligibility states that parents must 'demonstrate their inability to provide travel'. In this case, the inability is only perpetuated by the denial of funding for car modification. For participants and their families, this again creates a sense the NDIS is abdicating its responsibility to meet the additional resources required to meet a person's needs due to their disability.

## NDIS funded assistance at school

Families have reported that there is confusion and difficulty surrounding whether or not their NDIS funded supports can be accessed at school. This must be clarified with the education departments in each state.

In one case a participant, who was a student at a local primary school, was funded to have supports in class, to support both him and the teacher to better adjust to meet his learning needs. Instead of facilitating this, the school responded in a hostile manner and requested further information, despite the therapist having emailed a plan and outline of activities. This has delayed the implementation for weeks, as the school year ticks away.

In other cases, inconsistency regarding whether children can be pulled out of class for therapies has caused concern for parents. Family Advocacy supports inclusive education, meaning students with disabilities should not be labelled, or otherwise marked as different. However, in some cases this will be a question of balancing the learning and health priorities for the student. We recommend guidelines for access to therapies in school hours be produced between the NDIA and state education departments, so that some clarity and recourse is available when and if there are extenuating circumstances or the guidelines are not being followed.

# B. The consistency of NDIS plans and delivery of NDIS services

## **A recent survey from our families**

Recently, we asked families about their experiences of the NDIA planning process. We received 100 responses. People whose family member is participating in the NDIA responded at length, explaining their frustrations and also some successes with the new funding model.

Families said that despite the good intentions of the NDIS, many felt “worse off”. They are experiencing a myriad of problems in the planning process, with:

- inadequate support in the preplanning and with implementation of their NDIS plan
- poor communication
- lack of a genuine understanding of their support requirements
- and a lack of availability.

Not surprisingly, this has led to a spike in reviews and appeals. Our feedback is that the review process is slow, frustrating and stressful. All of this comes at a cost to families who are already struggling – not only to the National Disability Insurance Scheme (NDIS). An overwhelming number of families who responded to our survey feel their NDIS experience has been alienating, time wasting and has created mistrust.

One of the aims of the NDIS is to assist people with disability to live “an ordinary life” by enabling inclusion and participation in society. That means:

- to fully realise their potential
- to participate in and contribute to society
- and to have a say in their own future – just as other members of Australian society do.

It is our hope that the NDIS can achieve these outcomes of stronger social and economic participation of people with disability. It is important that there be some consideration placed on the cost of not achieving these aims – the negative social impact will ripple well beyond the financial cost. To ensure the success of the NDIS, the NDIA must provide certainty of support to help a person with a disability achieve their goals.



Rather than the current barriers, Family Advocacy recommends self-managed NDIS participants be properly supported by NDIA policies, its staff, the LAC's, the NDIS systems, and the Portal.

## Planning meeting needs to be documented

Would you have liked a draft of your plan from the first Planning Meeting?



In our responses to the above survey question, around 93 per cent said they wanted a copy of a draft plan.

### A draft plan is necessary

Michael says:

It's my information, but I wasn't allowed to see what the LAC was typing into the computer, nor was I allowed to have a copy. This is not in line with the NDIS Act. This would help stop some miscommunications. If we skipped the LAC and I had direct access to a planner would also have stopped miscommunications. I want a copy of that. I also want a draft copy of the plan for my perusal and approval. What insurance contract is ever done without seeing the terms and conditions, and agreeing to it! Now, like the majority of people doing plans now, I'll have to get a review. How is this faster or cheaper?

Julia says:

Not enough prior knowledge of the process and who needed to be involved. No notes of the first planning meeting received for approval. The plan took over a month to be accessible and did not reflect the discussions and agreements at the planning meeting. There was no procedure available to address these problems at this stage. The pricing list was difficult to relate to the plan as the item reference numbers weren't used in the plan. The whole process has been very frustrating and disappointing and is still going on for us. Local NDIA staff were poorly briefed regarding the process, although always tried to be helpful.

Like taking minutes of a meeting that reflect the issues discussed, participants and their families could check that the goals, information shared and supports requested were accurate. To ensure privacy is maintained, the portal could be set up so the participant could gain access to the draft plan using the participants' NDIS number. As we know, if information in the plan is incorrect or missing, changes to a plan will be required which sparks the need for a review. This could easily be prevented if the participant had a document to read and check. **We recommend that a draft plan is needed to avoid unnecessary reviews and to alleviate any anomalies or misunderstandings.**

### **Inaccessible: participant's relationship with planners**

The lack of transparency and power imbalance between the participant and the planner is a problem. The planner has power to determine the quality of the participant's life for the next 12 months or until review of the Plan. The planner has unlimited access to all of the participants' details about how they live, their life goals, their medical situation, their employment details and all about how their quality of life is "substantially reduced" as a result of their disability. Currently, it seems that no participant is given any information about their planner - no email, no phone number, in one case not even their surname would be provided. Due to these communication barriers with the planner, there appears to be a lot of time wasting.

In one case, Kathryn, mother of Tom, had approval for Assistive Technology subject to providing quotes, for a wheelchair that was very run down and too small for her growing seven year old child. The planner made contact with her Occupational Therapist (OT) regarding the quote provided. The OT attempted to call the planner for more than two weeks before she could finally speak to him. For a child who needs a comfortable wheelchair, two weeks is a long time to be in discomfort.

There needs to be a faster response time for communication from the planner. If the participant met their planner face to face, they could better understand the support needs of the participant, and they would have a far greater picture of the participant's needs and wants. This would ultimately lead to a better quality plan and far less applications for plans to be reviewed and cost the NDIA less in resources.

## **Plans in plain English**

We are receiving feedback from our families about the unclear written communication in the plan. There is a lot of jargon used that participants are unfamiliar with. Plain English is required.

In one case, a family received a plan with car modifications being denied with no proper explanation as to why they were declined, but simply a reference to a link with the Operational Guidelines. When reading these Guidelines, there did not appear to be any obvious reason why the car modifications were declined.

If English speaking families are having trouble understanding the plan, we only imagine how difficult it is for those that have English as a second language. As a result, it would be of great assistance if the Agency provided clear written communication in relation to what services can be utilised in each of the categories and in the case of being declined, a proper explanation.

## Supports before and after

Good quality pre-planning support is required. There is a need for participants to have support in the pre planning process to ensure the participants' situation and goals are understood. This could involve LACs or other groups that are community connectors.

This role of community connector is important in the pre planning process as they have a better chance to understand the intricate needs of the participant and be able to potentially marry them up with what supports exist in their community. This should allow for a more tailored plan as the participant will be more clear about what is available and know what to ask for in the planning meeting.

From what we have observed, the purpose of the LAC has been displaced from its originally intended form due to the rollout. In our understanding, the original intention of LACs was to support unfunded people with a disability with community development and addressing any barriers to pave the way to promote inclusiveness at all levels of society. The LAC was supposed to be the person who would, for example, go to Girl Guides, the Men's Shed or the Chamber of Commerce and find ways to make connections for people with a disability, whether it be for employment, volunteer work or for social connections and hobbies/leisure. If the Agency does not see this as the future role of LACs, a new role needs to be created to provide this very important community link.

Once a plan is granted, the right supports need to be in place to support families on how to implement their plan. Many families have expressed their confusion and lack of understanding of how to use it. Some families are not using the plan as they feel overwhelmed, do not have the confidence to do so and do not know where to start.

Taryn says:

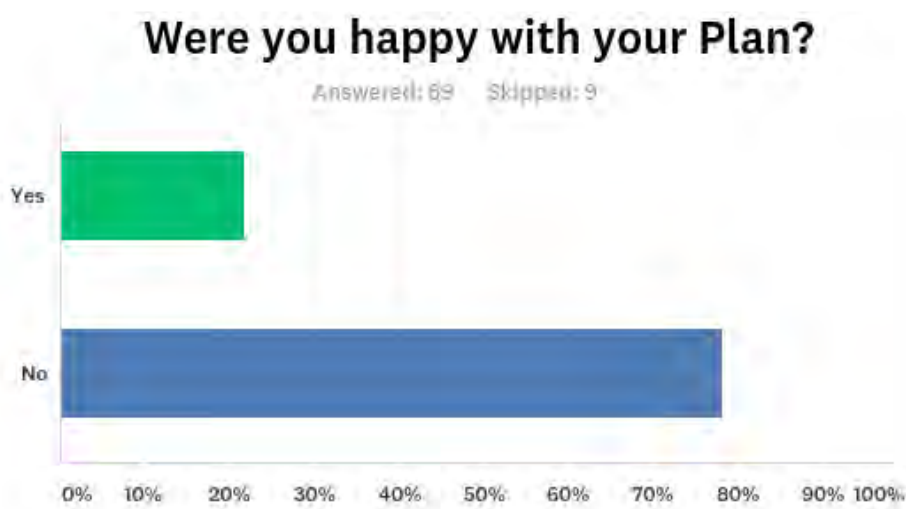
The pricing list was difficult to relate to the plan as the item reference numbers weren't used in the plan. The whole process has been very frustrating and disappointing and is still going on for us. Local NDIA staff were poorly briefed regarding the process, although always helpful.



Another respondent, Irene shared that she has had trouble navigating the system, the price guide is inflexible and she is getting mixed messaging from the NDIS workshops, the NDIS website and her LAC. She expressed it would be very helpful, especially for the first plan, to have a support person to help implement the plan. Irene commented that her LAC is so busy, she does not have time to help her.

Another respondent, Irene shared that she has had trouble navigating the system, the price guide is inflexible and she is getting mixed messaging from the NDIS workshops, the NDIS website and her LAC. She expressed it would be very helpful, especially for the first plan, to have a support person to help implement the plan. Irene commented that her LAC is so busy, she does not have time to help her.

## Majority of participants unhappy with plan



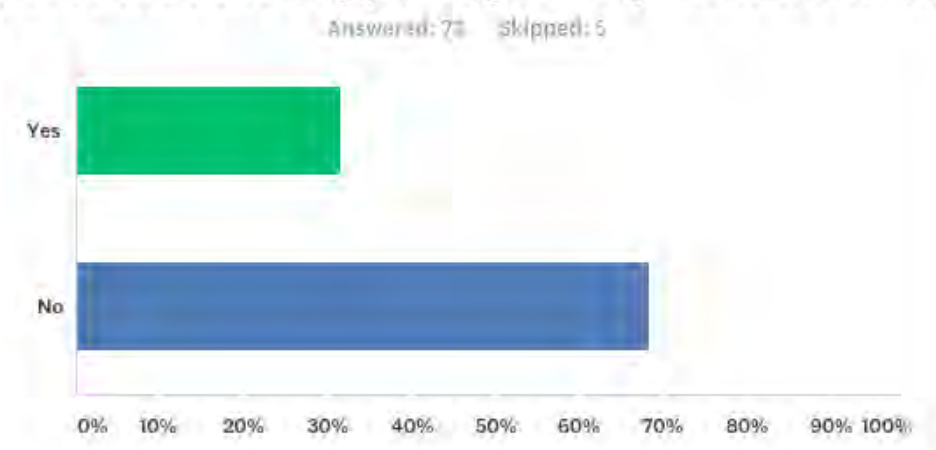
At over 78 per cent, the high level of unhappiness with the participant's plan makes it clear that the majority of our families did not feel the plan met their support needs and expectations due to:

- gap between support needs and plan
- the need for pre planning support
- poor planning process
- lack of capacity to change minor details without a review of the plan

# Large gap between support needs and the plan - planner unprepared or portal problem?

We are consistently receiving phone calls from bewildered families expressing that the plan they receive is disparate from the what they discussed in the planning meeting.

## Do you feel that the supports you require were understood?



In our responses from participants, over 68 per cent said they did not feel their support needs were understood, as they expressed:

### Gap in supports required and the plan

Janelle says:

Whilst [the planning discussion] was quite easy to do, the outcome and the funding was very much insufficient and didn't resemble the needs of my son. Having now to apply for a change in circumstance is a headache and as if I as a carer don't have enough to do now need to do this.

Jason, father of Leah, says:

A horrible, disappointing and disempowering experience. We have had our support for our profoundly disabled child cut by 70 per cent. We are up to our third review, having escalated to local MP, state MP right up to the CEO of NDIS. It is beyond appalling. It is clear that the NDIS is no more than a cost cutting exercise for the federal liberal party. They treat families with rhetoric, politics and a total lack of real respect and understanding. We will fight this all the way. Ironic, given this was a system which was meant to change all that. I could not be more disappointed and disillusioned in this system if I tried.

Alex says:

It was a complete disaster and caused terrible stress to all my family. It was as if they did the complete opposite of what I asked for.

Despite careful preparation about the goals for their person with a disability, it seems that many LACs and planners are not in touch with the support needs of the participant. The planning meetings require more in-depth conversations with competent planners or LACs. More depth and breadth in training is required for LAC's and planners. A much deeper understanding of what makes for an ordinary life for a person with a disability is needed. We will discuss this later in our submission under the section "Investing in LACs and planners".

Alternatively, it is possible that the NDIA computer system is limiting LACs and planners to be responsive to the specific needs of each individual. If this is the case, the NDIA must alter its computer programme so the portal allows for personalised information to be input into the system - not a cookie cutter approach.

## **Increase in review/appeal numbers due to poor planning process**

Poor planning has inevitably led to an increase in the number of reviews being requested. This will incur unnecessary costs for the NDIA and participants, and divert resources away from other, more valuable activities.

From our survey, a high number of unexpected plan reviews are being undertaken. This no doubt, has placed a greater strain on review processes as well as appeals.

Statistics from the NDIS website, reveal the following from 30th June 2016 to March 2017\*:

- Total number of appeal lodgements nationwide had risen from 63 to 161 (58 per cent)
- Total number of complaints increased from 1408 to 3154 (55 per cent)
- Total number of plan approvals rose from 30,281 to 78006 (61 per cent)
- Total number of reviews increased from 554 to 26,757.

It is worth noting, the statistics provided by the NDIA regarding reviews are not consistent. The report on 30th June, 2016 states internal reviews (a review of a decision by the NDIA) to be 772, with 262 relating to access decisions. Unfortunately, there is no equivalent table relating to internal reviews in the report on 31st March, 2017. It reveals generally, reviews are 26,757 which includes internal reviews as well as scheduled reviews - 12 monthly plan reviews. Hence, the dramatic increase from 554 to 26,757. It is very difficult for a member of the public to know the real number of internal reviews being processed.

Therefore, we are unaware how many internal reviews the NDIA have received for the corresponding period. If the Administrative Appeals Tribunal statistics are any indication, they may be in the same order of more than doubling over the last 12 months.

In the interests of transparency to participants and their families and supporters, we request the Joint Standing Committee recommend the NDIA report consistently in relation to the number of Internal Reviews, nationally and in each State, and reveal same publicly.

---

\* Statistics obtained from National Disability Insurance Scheme, COAG Disability Reform Council Quarterly Report dated 31 March, 2017, page 4, from NDIS website <https://www.ndis.gov.au/medias/root/heb/he8/8801054359582/COAG-DRC-Report-2016-17-Q3.pdf> and National Disability Insurance Agency, 11th Quarterly report to COAG Disability Reform Council, 30th June 2016, page 46, 47. <https://www.ndis.gov.au/medias/Report-to-the-COAG-Disability-Reform-Council-for-Q4-of-Y3-PDF-2.5MB>;



The NDIA needs to undertake more detailed performance reporting on review processes. Family Advocacy recommends the NDIA publicly report on the number of unexpected plan reviews, reviews of decisions, review timeframes and the outcomes of reviews.

## **Reviews have long and unreliable timeframes**

Many families stated that the review process had long and unreliable timeframes.

Kathleen, mother of Jason says:

First plan okay, although orthopaedic special boots were omitted. Then we had a 'change of circumstance' and have had a shocking time of it with no supports being accepted after five months. Even though all the paperwork/ OT assessments have been submitted.

Brian, father of Chris, says:

It has been a nightmare. Very poor communication and follow up on equipment requests taking four months to approve and then one has to wait 12 weeks for equipment. Also, an appeal lodged took nine months to find out we were unsuccessful as insufficient evidence. My son is worse off under NDIS than before.

Kristine, sister of Miriam, says:

The first plan was completely wrong. Four reviews later and lots of stress and the plan is ok for now.

Jacqueline says:

Too long to tell. Three plans in eight months - none of which were instigated by us but because planner had stuffed up. Had to appeal but appeal was dismissed as having 'no grounds'. Received a phone call this week by NDIS saying there had been a 'programming error' and they would like the opportunity to have a face to face meeting with them.

Taryn says:

My sons plan was handled very poorly, when we had our first visit it lasted under 30 minutes as the LAC's computer wasn't working, so over the next three days, two different people contacted me to finish the plan then on the third day, it was approved. As the plan came back under funded, I challenged it, and still not happy with the outcome.

The above examples show the review process itself requires improvements to reduce time delays.

### **Minor amendments to plans without triggering a full plan review**

The review process needs to be more efficient and fair. The fact that the whole plan comes under review can act as a deterrent for a participant to apply for a review, particularly given there is the unspoken but real threat that they might get less. Full reviews would be more costly and time consuming. Further, participants are unable to access the supports they need whilst they wait for their review to be heard. This is illustrated in the comments below

John says:

Never spoke with or saw a planner. Asked for a review and it took three months for a planner to actually contact me. When they did, they said that they could not be flexible with the plan, and that if it was to be reviewed now, the whole plan would have to be reviewed, not just the parts we needed reviewed, and as it was only four months until the current plan ended, that we should wait till then (September 2017) to have the plan looked at in more depth. We can never get a direct answer.

There is always someone else who has to get back to us. Just recently the participant has had a serious burns accident because of his disability. We need to get special equipment to eliminate the risk of further injury occurring. We called two weeks ago and we still haven't got anyone calling us back to see what can be done or to answer our questions or concerns about how we can get the funds to cover the special equipment needed.

Family Advocacy recommends the NDIA implement a process for allowing minor amendments or adjustments to plans without triggering a full plan review.

# C. Any other related matters

## Self-management supported by the NDIA

"The evidence strongly suggests a wide range of positive wellbeing outcomes from self-directed funding for people with disabilities and their carers, including higher satisfaction with life, more independent living, better continuity of care and lower levels of abuse and neglect. Self-directed funding appears to cost no more than traditional models of care, and may well cost less."

Inquiry Report on Disability Care and Support, Productivity Commission, 2011

Family Advocacy encourages self direction through the NDIS as being in the best interests of people with disability. Our organisation played a key role in pioneering self direction in NSW, via the Supported Living Fund. A participant can self direct in three main forms under the NDIS:

- Self management only
- Part Self management with Plan Management,
- Part Self Management/Plan Management/ Agency Managed.

We urge the Joint Standing Committee to include a recommendation in their final report that self management be properly understood and supported by NDIA staff, LACs and planners.

Currently, agency managed plans seem to be the default position. According to an NDIS provider forum attended in April, 2017, the figures provided were that 70 per cent of plans were agency managed whilst only eight per cent were self managed. We want to level the playing field. Barriers to self management are lack of agency support, participant awareness and capacity, and lack of support coordination.

Another barrier is the onerous process for sole-traders and small businesses to become registered providers. We acknowledge that safeguarding measures are in place to protect the vulnerability of a person with a disability. For example, a speech pathologist should be required to provide adequate qualifications, have an ABN and a Working with Vulnerable People Check, and even a First Aid Certificate.

But to put a business plan together makes this process too onerous and takes away any motivation to become registered. This barrier means sole-traders, such as therapists, will not be available to a participant who wishes to plan manage or agency manage as they can only use registered providers. There is no real “choice and control”.

We suggest there be levels of registration based on risk. The Agency needs to do a risk assessment of service providers perhaps categorising them into high risk and low risk. The higher the risk the more stringent the process in order to become a registered provider. The lower the risk, the less stringent the process. We believe this may facilitate the emergence of small boutique groups that provide supports to those participants that wish to self direct.

An additional barrier to self direction is the fact that for participants that wish to self direct their plan, but use a plan manager to assist them in the invoicing and payment process, are required to use a registered provider which is subject to the price guide. They may be steered away from taking the self direction option due to the lack of flexibility.

## **Investing in Local Area Coordinators and Planners**

LACs do not seem to fully understand what self-management means. There appears to be superficial knowledge of what options are available to the participant.

One family member reported that in their ‘first plan’ meeting, the LAC simply said they could agency plan or self manage but did not explain what this really means or provide any options of how that could work.

Another LAC told a family member that she should not self manage as it was too complicated and meant you had to get insurance.

A family member reported that an LAC told her she could either have support coordination or plan management but not both. This is completely incorrect and makes no sense.

The first refers to support in coordinating the plan and the second relates to how the Plan will be managed by the participant. One does not depend on the other.



In order to address this and promote self management, we suggest that the Agency develop a pro forma checklist which includes suggestions of what options might be available and to mark off to ensure this is done in each initial meeting and at the 12 month review stage.

However, this must also be coupled with more in depth training of LACs, as well as Planners to really understand what self management can look like and how it can work in a participants life.

Many people who have worked in the disability sector have no experience in self management. Different levels of training could be provided by the NDIA to staff depending on experience in the area of "self management".

Family Advocacy has produced webinars on self management and particularly in capacity building around self management. There are several good quality in-depth and broader training programmes in self management. We recommend the Joint Standing Committee put some recommendations forward to the NDIA and we can supply you with specific details in this regard.

### **More flexibility is required for payments to unregistered providers**

More flexibility is required regarding plan-managed participants being bound by the price guide. We suggest that more flexibility and greater inclusion for more informal supports would allow for true choice and control.

For example, one family with an adult daughter, Tina, who has Down syndrome, requires support to wash her own hair. Tina was told that she could not use the local TAFE students to wash her hair at the rate of \$15 but could pay for a support person to attend her home which would cost approximately \$80.

Being mindful of the financial sustainability of the scheme, it is more logical for the NDIA to be flexible about informal supports when the outcomes can make the NDIA dollar go further. This example highlights the need for more clarity around the restrictions of the price guide for participants who are plan managing

## Support self-direction: support coordination

The more “ordinary” a person’s life, there is usually more flexibility and less routine, particularly socially. This is illustrated by Katrina’s story:

In the case of an NDIS plan, it would be of great assistance to Katrina to take a lot of administrative time and pressure away from her family, if she were to have support coordination not just at the initial stage of her “first plan” but throughout the whole of her plan. This family’s experience is that the process of using the plan is very labour intensive. Katrina’s sister is required to manage the plan, arrange appropriate supports, book the shifts, receive invoices, and pay on the portal. This might seem like it could be routine tasks easily slotted into a person’s life but in practice it is not – due to the fact that Katrina lives an ordinary life, like all Australians, her social life is not routine. Her supports on the weekend can vary. If she has a family function for example, a camping trip over the weekend, her paid supports are not necessary. This requires Katrina’s sister to cancel her prearranged support worker which can take time emails back and forth to ensure the cancellation is confirmed.

Compounding this situation, is the fact that Katrina’s sister has employment and also has a son with a disability with an NDIS plan that she is managing. In this particular family’s situation, having a support coordinator to provide support to the participant over the duration of the plan, will not only greatly assist the participant but also the family member.

In this way, intermediaries can facilitate participant directed contact with paid, mainstream, community and peer supports. Provided they have proper resources and training and a level playing field exists. From the perspective of a person with a disability and indirectly their families, we believe that “being done to” needs to be undone. Support coordinators can help pave the way in this direction, if the NDIA plans and culture enable them to.

Greater flexibility is required in the system regarding the use of support coordinators throughout the duration of a participant’s plan. For some people with a disability, self-direction might not be realistic unless the proper supports and scaffolding is in place to make that happen. We acknowledge that people have the flexibility to part self-manage and be part agency managed. Others may prefer to self-manage and be part plan managed. To enable this will require flexible support coordination.

In one case Karen, mother of Jack, requested a support coordinator due to the complexity of her son's issues and was denied a support coordinator but instead granted 20 hours of interpreter services, something that was not required and not helpful. Karen was born in China but is very articulate speaking in English. She had no recourse to argue that she was eligible for a support coordinator because there is no public document that outlines this eligibility criteria.

Currently, the NDIS website does not provide clear guidelines as to when a participant is eligible for support coordination. For this reason, greater transparency is required in relation to the eligibility for support coordination.

## Conclusion

People with disability and their families need the NDIS to work, because when it doesn't, it costs them:

- the supports they need to have good lives,
- time,
- energy
- and stability.

It may even lead to people with disability and their families being in cycles of crisis – something the NDIS was set up to avoid. Fortunately there are solutions, in the form of:

- advocacy funding
- a draft plan that lets participants and their nominees check they've been understood
- transparent and accessible planners
- clear and plain English communication
- support for plan implementation
- a short process for minor amendments to plans
- reasonable time frames for full reviews
- support for self-management including:
  - more uniform and intensive training for staff
  - support co-ordination
  - and flexibility.



Submission to the Joint Standing Committee on the National  
Disability Insurance Scheme (NDIS) into the Transitional  
Arrangements for the NDIS

**Family Advocacy**  
(02) 9869 0866  
family-advocacy.com  
PO Box 502, Epping, NSW, 1710  
AUSTRALIA