Submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) Inquiry into NDIS Planning

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TERMS OF REFERENCE:

As part of the committee's role to inquire into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS), the committee will inquire into and report on NDIS Planning, with particular reference to:

a) the experience, expertise and qualifications of planners;
b) the ability of planners to understand and address complex needs;
c) the ongoing training and professional development of planners;
d) the overall number of planners relative to the demand for plans;
e) participant involvement in planning processes and the efficacy of introducing draft plans;
f) the incidence, severity and impact of plan gaps;
g) the reassessment process, including the incidence and impact of funding changes;
h) the review process and means to streamline it;
i) the incidence of appeals to the AAT and possible measures to reduce the number;
j) the circumstances in which plans could be automatically rolled-over;
k) the circumstances in which longer plans could be introduced;
l) the adequacy of the planning process for rural and regional participants; and
m) any other related matters

Overview

Family Advocacy provides advice and support to families so they can advocate with or on behalf of their family member with developmental disability (hereinafter disability). Our goal is to advance and protect the rights of people with disability so that meaningful lives can be enjoyed by experiencing the same opportunities and living conditions as the majority of Australians. Our work includes representing the rights and interests of a person with disability to Government regarding legislation, policy, funding, monitoring and practice in areas that impact detrimentally on people with disability.

Family Advocacy was founded and is governed by families of people with disability and is funded by the New South Wales (NSW) and Federal governments. One of our initiatives, Resourcing Inclusive Communities, aims to assist families to develop skills and confidence so that they can support their family member to have more choice and control over decisions and supports that facilitate individualised and normative lifestyles. This includes making the most of emerging opportunities for self-directing supports and to use creative and innovative models of support through individualised funding.

In this way, we believe our purview lies in alignment with the overall objectives of the National Disability Insurance Scheme (NDIS) Act (1 July 2013), with a similar aim to provide transformational benefits to the lives of people with a disability. Putting the person with disability at the centre of the decision making with regard to arrangements and supports is a critical component of this.

Family Advocacy appreciates the opportunity to provide input to the Joint Standing Committee on the NDIS on its Inquiry into “NDIS Planning”. This submission is based on a survey of 224 people with disability and/or their family member. It is shaped by the accumulated knowledge of families over nearly 30 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 people with disability and families as the NDIS has rolled out. For confidentiality reasons, the names of the parent and their child with disability have been purposefully changed. For ease of reference, we have used the same alphabetical numbering system as per the Terms of Reference.

Executive Summary

Recommendation 1: *The Joint Standing Committee on the NDIS recommend State and Territory governments provide funding in perpetuity for disability advocacy.*

Recommendation 2: *The NDIA address the need for cultural change for staff to be genuinely person-centred.*

Recommendation 3: *The Planner needs to respect the family as the natural authority and have a flexible approach to people with complex needs that is person centred rather than a one size fits all approach.*

Recommendation 4: *Provide more in-depth training based on values and disability rights, for all staff including LACs, NDIA planners and the 1800 help desk in order to properly understand the needs of a person with disability, treat them with dignity and respect, and have a fulsome understanding around self-management.*

Recommendation 5: *Increase the overall number of planners (with proper training) and the time they are allocated to be available for each person with disability*.

Recommendation 6: *That more supports be provided to the person with disability and their family member before an NDIS planning meeting, particularly when self-managing.*

Recommendation 7: *A draft plan is needed to avoid unnecessary reviews and to alleviate any anomalies or misunderstandings.*

Recommendation 8: *The NDIA adopts further measures to reduce the time it is taking to process reviews.*

Recommendation 9: *Plain English, as well as using understandable and consistent language, be used in all verbal and written communication.*

Recommendation 10: *Where the person with disability and/or their family agrees, plans could be automatically rolled-over.*

Recommendation 11: *In rural areas, more flexibility in plans is required to allow for the "thin market".*

Recommendation 12: *Invest in the promotion of self-management of funding via the capacity building of the person with disability and their family member.*

Recommendation 13: *A Budget Breakdown sheet be automatically provided to participants along with the draft plan*.

Recommendation 14: *Create a comprehensive toolkit of local resources*.

Introduction

From the information provided by families supporting their family member with disability, whilst there were a few good experiences, on the whole, many people with disability and/or their family member have had to face a myriad of problems in the NDIS planning process. From our recent survey, the majority of people with disability and/or their family member have experienced:

- lack of access to much need independent advocacy
- poor communication
- lack of genuine understanding of support requirements
- lack of understanding regarding self- management
- lack of support in the planning process
- lack of accessibility, transparency and flexibility from their planner
- poor responsiveness to their internal review applications
- lack of information of local resources.

Not surprisingly, reviews and appeals continue to be an issue and all of this comes at a cost to people with disability and their families. An overwhelming number of families who responded to our survey feel the NDIS experience has been alienating, time wasting, traumatising, expensive, and has created mistrust and disillusionment. This highlighted the need for independent advocacy, to ensure that people with disability have their rights promoted and protected; and that support to advocacy was independent from the funding system and that the need is greater than ever.

It is our hope that the NDIS can achieve the intended outcomes of stronger social and economic participation of people with disability. To ensure the success of the NDIS, the NDIA must provide certainty of support to help a person with disability achieve their goals. Family Advocacy has provided a number of recommendations with a particular focus on supporting those that elect to self-manage their supports. We ask these recommendations be accepted by the Joint Standing Committee on the NDIS and communicated to the NDIA.

Family Advocacy would welcome the opportunity to provide evidence should there be an upcoming hearing in Sydney.

The need for advocacy

Before we provide input specifically in relation to the Terms of Reference, we must highlight the absolute necessity of advocacy in the NDIS Planning process. The introduction of the NDIS has created significant change in the sector and for people with disability. As a result, the current problems with NDIS from a planning and delivery perspective have resulted in a greater need for independent disability advocacy.

Our families have expressed shock that so much advocacy is required on their part under this new system. They want the NDIS to be a success but have found the need for advocacy due to many barriers in the system, which are discussed below. Families supporting their family member with disability want to be heard and to see the system improve, but are frustrated and exhausted.

On an individual level, our advocacy, representation and information has provided essential supports to enable people with disability (and their family representative) to obtain the appropriate supports through the NDIS so that they can be included in the community. On a systemic level, no system is perfect. This inquiry is one of many where we, and other disability advocacy organisations, have provided submissions to State and Federal governments as well as directly to the National Disability Insurance Agency (NDIA). Systemic advocacy provides an alarm bell to alert decision makers where there are concerns and barriers to enable the NDIA to respond to failures in the system, prevent unnecessary cost, time wasting, and avoid problems before they blow up into preventable tragedies.

Disability advocacy is distinct from the functions funded under NDIS, including the Information, Linkages and Capacity Building (ILC) component of the NDIS. ILC funding does not replace the need for funding for disability advocacy. The Government' s own guidelines state that “we will not fund individual or systemic advocacy in ILC.”

With the introduction of NDIS, the NSW Government decided to redirect all its NSW disability funding to the Federal Government, including the funds for disability advocacy, representation and information organisations. After a concerted campaign by people with disability and community groups, in early April 2018, the NSW Government announced interim funding for disability advocacy support of $13 million per annum but only until June 2020.

Without secure long-term funding commitments from the NSW Government, the 10% of people with disability provided with an NDIS funded plan, won' t have access to an independent champion to help them navigate the fledgling NDIS system. Disability services providers, the NSW Ombudsman and the Productivity Commission have noted the crucial role of funded disability advocacy support, particularly with the introduction of the NDIS. For the 90% of people with disability not receiving NDIS funding, the loss of disability advocacy will mean an even greater gap in access to supports and being included in their community.

State Governments have a clear responsibility for ongoing funding to ensure that people with a disability will always be able to turn to local, independent advocates when they need them. The Federal Government, through its Assistant Minister for Disability, and the Minister for Social Services, has made it clear that state governments need to maintain ongoing funding for disability advocacy.

Independent reports such as the 2011 Productivity Commission Inquiry into Disability Care and Support noted that advocacy functions and their funding “should lie outside the NDIS, reflecting the potential conflict of interest that would arise were the NDIS to fund advocacy bodies whose role was to challenge the disability system overseen by NDIS. Current funding arrangements through state and territory governments should continue.” In 2017, the Productivity Commission again confirmed that State Governments are responsible for funding disability advocacy, separately to any handover of disability funding under arrangements for NDIS.

It is time to ensure people in any State or Territory will always be able to turn to independent specialists in disability advocacy when they need them.

Family Advocacy calls on the Joint Standing Committee on the NDIS to make a recommendation as part of this Inquiry into NDIS Planning that all State and Territory governments provide funding in perpetuity for disability advocacy, representation and information services for people with disability.

Recommendations

Recommendation 1: The Joint Standing Committee on the NDIS recommend State and Territory governments provide funding in perpetuity for disability advocacy.

(a) the experience, expertise and quality of planners

There was a mixture of responses saying planners vary greatly both in knowledge and attitude. Some can be arrogant and aggressive and others were considered caring and supportive. On balance, there were more comments stating planners were not experienced, had a lack of understanding of the needs of people with disability and that their approach was far from person-centred. It was also mentioned that ideas generations and suggestions from planners was lacking.

Inflexible approach, not person-centred

> *The planners aren't showing initiative of innovation or thinking outside the box. It’s very much a tick the box approach. The NDIA needs to understand that different things work for different people. All people with Autism or Intellectual Disability do not require exactly the same treatment, help or intervention.*

> *They may have traditional ideas about support such as group homes and day*

> *programs but lack any knowledge of supporting people in individual ways in the community.*

> *The planner was amazed that my daughter has such an independent individualised life however they didn't show much interest in how this came about. It was like 'magic' or 'luck'. They also didn't understand at all the nature of her life being in community rather than segregated disability services demonstrated by their suggestions of traditional segregated options.*

> *We have asked to consider innovative ideas. In all cases we are sure the Planner has not understood. Only on one occasion has a Planner taken the time to talk to us about the innovative idea that was outside the box. Planners as we see it are time poor, are under the pump to get plans out and approved. Have not got the time or willingness to talk with participants or their nominees. Our example our son started a very small business to create an opportunity to better build community connections. The business has grown so his support needs to overcome the challenges from his disability to work more independently in the business has grown. We proposed in his latest plan review of the support needs he requires to build his capacity to work more independently in his business. The Planner without knowing our sons personal capabilities within the business will only guess or apply his own thinking on what our son requires. The Planner needs to listen to the LAC and talk and LISTEN to the family*

One of the principles underlining the NDIS is to be person-centred. However, in practice, planners have a strong tendency to want to fund group segregated setting over individual support and attempted to be very pervasive to this end. This reflected the mindset of the outdated and traditional approaches to program supports for people with disability in which the NDIA purports to want to move away from. A common experience of families was that when more normative support arrangements that were individualised and connected to community were sought, it was common for planners to continue to strongly push the segregated options. Even when families felt that a strong case for funding had been expressed and documents were presented at the meeting, the plan would still come back representing segregated arrangements. This was very concerning for many families and life limiting for the person with disability.

The general view expressed by families is that there needs to be a focus on individualised funding, not group funding; and more flexibility in how to use the funding. Families have explained that it seems to be a formula where the computer system uses a drop down box for a single category of disability, which is very limited when attempting to fulsomely describe a person's disability. It does not adequately reflect a person with multiple disabilities and the multiplication of complexity when additional disabilities exist - resulting in people not getting funding in their plans that are personalised.

One example provided was about Jason, a young adult with complex mental health issues who would at times be hospitalised for months. Jason found success in an individualised well-being program with a particular psychiatrist which meant he did not need to be hospitalised for eighteen (18) months. His planner told him he had to do this in a group situation and would be given half the funding. This mentality illustrates a one size fits all approach.

Lack of understanding, lack of willingness to understand

> *I do not believe planners have sufficient understanding of the reality of disability. They are required to follow the guidelines of "reasonable and necessary" with insufficient awareness which can result in distressing discussions and outcomes.*

> *They do not try to understand the complexity, they do not read professionals' reports before making decisions, they are unable to comprehend and interpret the document, and this leads to uninformed planning and assessments.*

It was regularly commented on by families in the survey that planners did not read the myriad of reports that are demanded by the NDIA. This was seen as insulting and disrespectful to people with disability and families who have done their best to comply with the NDIS process which costs them considerable time and expense.

Recommendation 2: The NDIA address the need for cultural change for staff to be genuinely person-centred.

(b) the ability of planners to understand and address complex needs;

> *My family has been most fortunate to have access to a knowledgeable and proactive*

> *NDIS planner, who made every effort to truly work with my family to understand us and most importantly, my son's needs.*

> *The Complex pathways Unit has been very good and significantly improved engagement and responsiveness.*

> *Yes, her planners have taken the time to engage in meaningful discussions with my sister with patience, making sure that my sister was heard and understood. I believe this could not have happened if she had not had the same planner who had remembered her from the previous year.*

We would like to acknowledge the positive experiences that some families have had when planners have shown patience, listened carefully to both the person and the family and valued a collaborative relationship centered around the person with disability and their life. Sadly, this positive account has been drowned out by strong sentiment that planners are lacking in their ability to understand and address complex needs.

> *My child has complex disabilities and therefore requires a great deal of support and I don't believe the planners have any idea of what it takes to care for a child like this.*

> *Having worked with two planners, one was very good and listened and supported what we were trying to achieve. The participant has very particular support needs and she could see them and acted accordingly in executing the plan. The second planner showed no understanding of the participants needs, argued that sections of funding were no longer being provided by the NDIS when in fact they were. Her demeanour was quite confrontational, and she demonstrated that she lacked the ability to listen and deal with the plan preparation as a cooperative process.*

Allan is a family member whose adult son, James, has very complex needs including behavioural issues. He had been self-managing his son's supports directly for fourteen (14) years prior to the NDIS rolling out. To his credit, with some creative and lateral thinking, he had managed to obtain a meaningful life for James with great opportunities to achieve valued roles in his community. Importantly, these socially valued roles have also assisted James' behaviour management issues so much so that no therapy is required. Clearly, Allan knows his son best and is the natural authority on James' support needs.

When he received his first plan, his planner told him that he could not use the supports in the way he had been for the last fourteen years. This had serious implications from a behaviour management perspective. To change the routine after such a long time would induce anxiety which would manifest in a physical way thereby creating a safety issue, as James is a large adult male. With some advocacy assistance, further investigation at the senior level of the NDIA (which took several months), revealed that the planner was incorrect.

The above example highlights that the importance of the NDIA recognising that the family is the natural authority for their family member with developmental disability. Families ought to be recognised as having credibility and experience in understanding what are the most optimal support arrangements for their family member with disability. The NDIS needs to ensure that it is flexible to allow for the fact that one size does not fit all and to allow for creative support arrangements outside of the traditional approaches used historically for many people. This will take intentional effort from the NDIA in relation to rethinking its processes and ensuring that contemporary quality training is provided to its employees. This approach is the premise of the disability sector changes so it is about recalibrating the intent of the scheme to the current reality.

Recommendation 3: The Planner needs to respect the family as the natural authority of the person with disability and have a flexible approach to people with complex needs that is person-centred rather than a one size fits all approach.

(c) the ongoing training and professional development of planners

Flowing on from the point raised in (b), as part of ongoing training, planners need to learn to be more flexible in their approach and to have a much deeper understanding of contemporary and innovative support arrangements for a person with disability. The following examples show the need to be able to think outside the box in order to be able to achieve the objectives of the NDIS, to improve social and economic participation and live a more independent and inclusive life.

In the example above under quality of planners the parent spoke about the planner thinking it was magic or just luck that her daughter had such an individual and independent life. This shows a clear need for more values based thinking and training to improve the knowledge and understanding of planners and so improve the quality as well.

> *My son has his own business which I have set up, and needs individualised support to travel to work places/ be supported and to manage ongoing health issues. The planner sees him as not being disabled enough to require one on one support (my words not his) and thinks he would be better suited to be in an environment where he can be supported 1:3 (and saving the NDIS money). We have never used these types of services as we are committed to an inclusive lifestyle for our son and want him to have a good life like his peers and siblings!!!*

The above point reiterates the importance of NDIA employees having training on contemporary and innovative supports. Contemporary support arrangements that are individualised around the person are not new and should not have to be proven to the planner and this significant barrier can only be overcome by appropriate training and changes to processes. It also indicates a potential conflict of purpose of the scheme from the top down with a cultural shift towards the scheme addressing value for money rather than innovation that brings about independent outcomes for people with disability. This can also be addressed through values based training and improved communication internally.

There is strong feedback from families that there is a large vacuum of knowledge about self-management on the part of LACs and planners. There is a need for better training for NDIA staff based on values, rights and the many positive success stories associated with a person or nominee self-managing their funding. One LAC told a family member that she should not self-manage as it was too complicated and meant she had to get insurance. Another planner told a family member at the annual review that if she wanted to self-manage, she would have to pay for all the supports upfront, and then apply to the NDIA to be reimbursed. Without the correct knowledge or understanding, it appears the LAC/planner are filling in the gaps and providing their own opinion on self-management, even when it is incorrect. The notion and practice of self-management is not a new notion for many people across Australia. The NDIA and its staff need to be much better equipped to support the possibility of this and it cannot be addressed without appropriate and consistent training.

Proper training is also required for LACs/planners on the types of management - Agency managed, Plan managed, Self-managed - so they can understand and communicate accurately what self-management and plan management is, and how to best support the person with disability. The conduct of LAC/planners should also not reflect their own value judgements in this regard with their role being to provide impartial and informed support to the participant and their family.

Recommendation 4: Provide more in-depth training based on values and disability rights, for all staff including LACs, NDIA planners and the 1800 help desk in order to properly understand the needs of a person with disability, treat them with dignity and respect, and have a fulsome understanding around self-management.

(d) the overall number of planners relative to the demand of plans;

Only the NDIA can truly comment on this with authority. However, the statistics we can provide are: 60.63% of people with disability and/or their family member did not have timely access to their planner. We are unsure if this is due to the poor quality time management of the planner but we suspect it is due to the fact there are not enough planners relative to demand.

Families have mentioned long wait times for internal reviews, delay of any form of communication, lack of availability and accessibility to the planner, a lack of transparency and power imbalance. 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.

> *The process of contacting a planner is convoluted and bureaucratic. No direct access ‘allowed’. Emails get lost through central processing. I’ve taken to delivering by hand to the local office important information that needs to go to planner. It is up to their whim and timetable to contact you. If they are unable to respond or don’t answer, they put the responsibility onto you to follow up. They don’t arrange a convenient time to call you-you are supposed to drop what you are doing whenever they call and address very challenging issues over the phone and on the spot. In other words, the communication is very poorly thought through, and there is definitely a very uncomfortable power imbalance built into the system.*

> *No access to the Planner. I went into local office four times to try and speak with her and she was unavailable each time. No feedback from Planner, she did not contact me at all after my visits to NDIS office even though I was assured she would. No follow-up. The Planner stated she would contact my daughters' Occupational Therapist with information regarding NDIS contact for Home Modifications - this did NOT happen. Nor did it occur after the OT emailed Planner requesting information.*

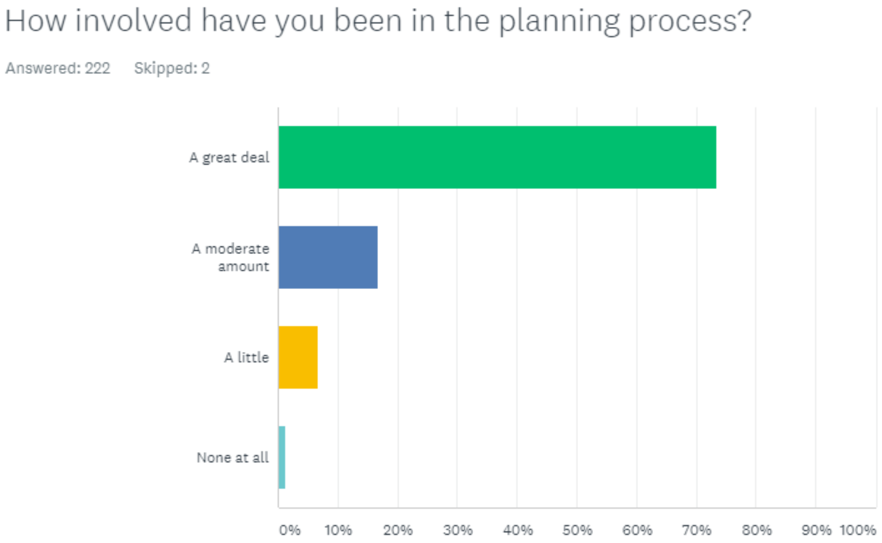
Clearly, there needs to be a faster response time for communication from the planner, better accessibility and clarity around the communication process. This will go a long way towards managing everyone's expectations and avoid frustration.

This could be solved by having more planners provided they are well trained, good quality planners. More poor planners will create more problems. If there were more good quality planners, it is hoped there would be more time allocated per person, more chance for the person with disability to meet their planner face to face, to better understand their support needs, and be more available for follow up with questions/issues. 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.

Recommendation 5: Increase the overall number of planners (with proper training) and the time they are allocated to be available for each person with disability.

(e) participant involvement in planning processes and the efficacy of introducing draft plans

(e)(i)There is a need for supports prior to the NDIS plan meeting to improve participant involvement



For people with disability and families to be prepared and involved in the planning process then good quality pre-planning support is required. There is still a need for participants and where available their families to have support in the pre-planning process to ensure the participants' situation and goals can be clarified and understood. The graph shows the heavy involvement our family members have in the planning process. 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 could be positioned to better support and advise participants and families to the existing mainstream community activities and groups that could be considered in the planning process. This would allow for more tailored plans that would enable the participant to be more actively involved in their community. The NDIA contracted the Community Resource Unit (CRU) to develop an extensive rain the trainer resource with the intention of addressing the lack of skills and experience of LAC across Australia and to ensure consistency of knowledge and approaches. However, this training resource has not been implemented. If this training was implemented appropriately it could support the capacity of LACS to undertake their roles and significantly reduce the current issues pertaining to under developed skills and knowledge.

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 the LAC was to support unfunded people with disability around community development and addressing any barriers to pave the way to promote inclusiveness at all levels of society.

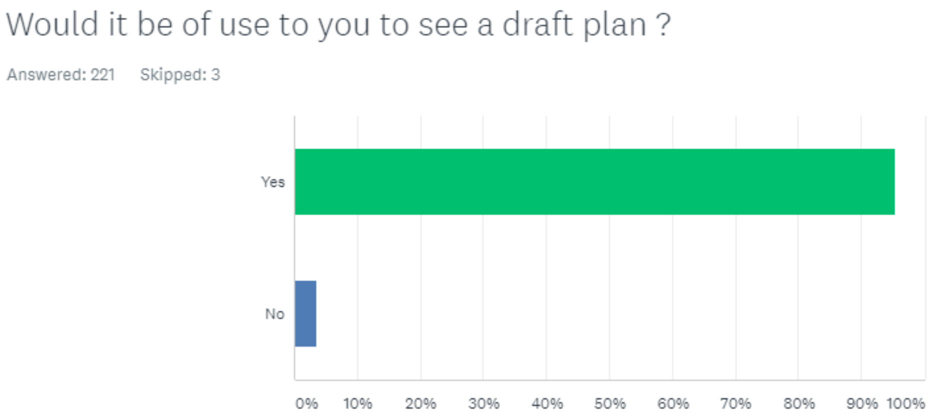
The LAC was supposed to be the person who would find ways to make connections for people with a disability, whether it be for employment, volunteer work or for social connections and hobbies/leisure. If the Agency does not see this as the future role of LACs, a new role needs to be created to provide this very important community link.

An example of the effect of the lack of support in pre-planning is where one family member, who has multiple children with disability, has decided not to apply for the NDIS for one of her children because she knows what was involved for her other children and feels it is all too hard for her, both energetically and emotionally. This goes against what the NDIS was intended to achieve.

To provide support in pre-planning, one suggestion made was for the NDIA to provide a tool on a mobile phone App or website. This could include some examples of goals or supports provide definitions and explanations of the NDIS jargon, an explanation of the criteria being used, and a Reasonable and Necessary checklist.

Recommendation 6: That more supports be provided to the person with disability and their family member before an NDIS planning meeting, particularly when self-managing.

(e)(ii) There is a need for a draft plan



In our recent survey, 95.48% were in favour of a draft plan. The Joint Standing Committee on the NDIS needs to look at this seriously. We have been making this recommendation for several years now. Currently, a person with disability walks away from their planning meeting without any record of what was discussed, and what was understood and/or agreed upon nor are they allowed to see what the LAC/planner is typing into their computer. This is alarming as it has been historical practice in the service system that a person with disability and their family had the opportunity in most cases to sign off on a plan prior to it coming into place. The fact that there is no draft plan is a significant step backwards. We believe many reviews could be avoided if a draft plan was implemented. In addition, this is causing incredible stress, frustration and mistrust between participants/families, LAC's and NDIA employees.

The NDIA is making decisions unilaterally rather than it being a consultative process. There is a significant imbalance of power being experienced in this process. A person with disability ought to have the power to correct an administrative error without going to review and all the delays and stress this causes even if it means allowing a longer period of time for the final plan to be completed. Our concern is that the NDIA is not listening to families about the importance of seeing a draft plan. It is completely unacceptable that a person does not get an opportunity to see a draft plan and this needs to change.

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, that would also have stopped miscommunications. I want a copy of that. I also want a 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 their NDIS plans, I'll have to get a review. How is this faster or cheaper?*

A draft plan would be similar to receiving minutes after a meeting, providing information 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.

Recommendation 7: A draft plan is needed to avoid unnecessary reviews and to alleviate any anomalies or misunderstandings.

(f) the incidence, severity and impact of plan gaps;

> *Poor attention to detail. For example, two pieces of equipment approved, but funding not entered into plan, so light-touch review required to fix, causing delays of multiple months. Just one of many examples of administration errors causing real life problems that seem to be incredibly difficult for NDIA to fix.*

> *I wanted to self managed and I was given NDIA managed. When I tried to get it changed nothing happened for 6 months and I had to get my local politician to help expedite the process. We were not given enough funding as well as some items being left out completely.*

One family told us they called the NDIS office every week for 16 weeks and went into the office twice. She was eventually told "if you don't like it, write to the Minister", which is terrible customer service and not asking for anything beyond the bounds of the legislation.

The impact of plan gaps to the person with disability and their family is obviously distressing, time consuming, frustrating, creating mistrust and lack of confidence in the NDIA. More importantly, the person with disability is missing out on important supports whilst waiting for the plan gaps to be reviewed.

> *12 months with no response despite numerous phone calls. Until 6 weeks out from the end of the first plan, I received a phone call telling me it wasn't going to be looked at. It would be put at the front of the next review. Offered an early review. Didn't happen.*

(g) the reassessment process, including the incidence and impact of funding changes;

There was a resoundingly repetitive message from families that each year, the funding in plans has reduced.

> *Our internal review took about 8 months to be heard and it was only this quick because we applied political pressure through the minister & our local Federal member.*

Many families have shared that they have had to contact their local Federal Member of Parliament (MP) for assistance in relation to NDIS matters due to sheer frustration from time delays, not receiving any response, not having a particular person they can contact due to the lack of transparency. The feedback was that after significant delays with no responses, assistance from their MP seemed to speed up the process.

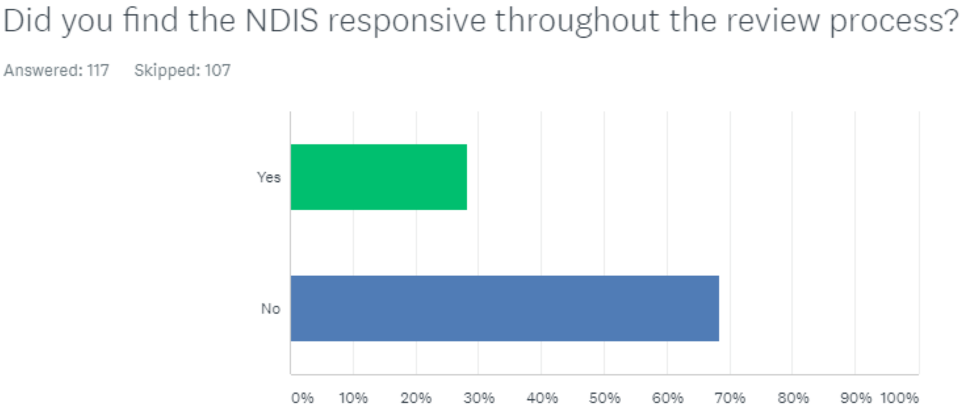
It seems unnecessary to overload MPs offices with NDIS complaints. The reassessment process should be fixed in order that all families' experiences are timely and responsive.

Another impact of funding changes is the example below, which shows the impact of the current lack of flexibility in funding.

> *I asked for private swimming lessons as these were good therapy for upper body. These are not approved. Exercise physiology was approved that does a similar therapy but at 3-4 times the price. Dancing as a therapy has reduced the need for wearing a leg brace and medical interventions but NDIS won't fund dancing.*

These points once again clarify the need for the NDIA to be flexible and individualised in their approach to what it considered 'reasonable and necessary'.

(h) the review process and means to streamline it



Survey results reveal 68.38% of people with disability and/or their family member did not find the NDIS responsive throughout the review process.

> *Over 12 months, our review application was lost, then misfiled. Denied, then approved after ombudsman input. At 9 months, we finally sat down with a senior planner for 6 hours of meetings, we waited weeks with no update, then heard he had resigned and didn't leave notes. We waited another few months for a new senior planner to pick up the plan had to start again with another 4 hours of meetings, this coincided with the time for the annual review and we are still unsure to this day if the internal review or annual review was what was completed. The outcome was another insufficient plan but by this time I was too exhausted and traumatised by the process to keep challenging. Planner was promoted into another area so lost access to anyone to support us within the NDIS.*

There is clearly a need to reduce the time delays for Reviews. Despite the NDIA's attempts at addressing the backlog of Reviews, many families continue to contact us for assistance due to lengthy review periods. This is not acceptable.

One family member suggested that there should be some type of motivation for the NDIA to speed up their processing time. Reviews are processed within a reasonable timeframe such as three months or the participant receives what they are contesting. Alternatively, the matter is taken out of the NDIA' s hands for an independent body to decide.

Referring to the legislation the CEO must make a decision on whether to review a section 43 review application within 14 days or the review reverts to a section 100 and thus triggers an annual review. This causes unnecessary and extensive delays in time as well as clearly impacting the person with disability being well supported. This internal process needs to ensure the review is properly considered within this time frame rather than be a default due to time inefficiencies.

To reduce the number of reviews in the first place, we suggest all of our recommendations be adopted. This would mean having a competent planner with a person-centred and flexible approach that listens to the person with disability and/or their family, has adequate time in the planning process and follow-up process and provides a draft plan to iron out any errors/misunderstandings.

Recommendation 8: The NDIA adopts further measures to reduce the time it is taking to process reviews.

(f) the incidence, severity and impact of plan gaps;

We are receiving feedback from our families that the written communication from the NDIA is unclear, and confusing. This includes the plan itself, the letter that may accompany the plan or the letter rejecting requests for support. There is a lot of jargon used that participants are unfamiliar with, there are no explanations supplied, and often the language describing support in the plan differs from the language in the portal. The letters often only refer back to a section of the legislation and this can be both overwhelming as well as inaccessible for people to be able to understand and respond to.

One family member, who is a native to the English language, educated, well resourced and knowledgeable about the NDIS has expressed how difficult the planning process has been in terms of understanding the language, the jargon, the meaning and objectives of the Act, and how to properly prepare. If English-speaking families are having such difficulty, we can 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 NDIS plans were provided in plain English with understandable and consistent language, if the Agency provided clear and consistent written communication in relation to what services can be utilised in each of the categories, with clear definitions. In the case of being declined certain supports in an NDIS plan or internal review, there needs to be an appropriate explanation as to the reason why the supports are not being provided. If there is insufficient information, that should be clearly communicated and the information required should be specifically requested.

Similar to (h) above, if all of the recommendations in this submission are adopted, this will contribute toward reducing the incidence of appeals to the AAT. If good quality planners are well trained, accessible, available, respond in a timely manner, are flexible in their approach, person-centred, a draft plan is provided in plain English and people with disability and their families are properly supported prior to the planning meeting, we are confident that the number of appeals to the AAT would decline also.

Recommendation 9: Plain English, as well as using understandable and consistent language, be used in all verbal and written communication

(j) the circumstances in which plans could be automatically rolled-over

Given the energy, stress, time and expense preparing for a planning meeting, the majority of people with disability and nominee's agreed to the concept of an automatic roll-over. The circumstances would be appropriate where the needs remain unchanged and the person with disability and/or nominee agree to it. There should be an annual reminder giving the person with disability and their family the option to review if there happens to be a change of circumstances/life transition/needs.

> *Of course, recurrent funding makes so much sense. You have security and certainty. Would free up planners and administrative work. That's what we had under the old system in NSW. Your life would be much easier. You could have a review only when needed, change in circumstances etc*

> *Yes I would prefer to have the plan automatically rolled over so long as there is no decline/change in circumstances. Rolling over where funding has been sufficient would hopefully free up workload of planners, speed up processing times, decrease stress/anxiety of review processes and save money re specialist reports etc.*

Families with very young children did not believe it would be a good idea as their child's needs are constantly changing. Some families with younger children suggested a two year plan would be preferred. This would allow some of the longer term activities to be completed and remove the stress of having to reestablish providers and service level agreements so frequently.

> *I understand with young children its hard to determine issues arising but if we are happy with what would be an inspection of the plan before its finalised and if we were happy with the outcome than 2yrs would be a huge relief of not having to waste funds for reports and the stress of possible reviews if needed.*

Recommendation 10: Where the person with disability or nominee agrees, plans could be automatically rolled-over.

(k) the circumstances in which longer plans could be introduced

See (j) above.

(l) the adequacy of the planning process for rural and regional participants;

There are many barriers for people with disability living in rural and regional areas, particularly given the “thin market” in these areas. The lack of consideration of transport funding for people in rural areas was raised. One family wanted to self-manage as they felt it was a better use of the funds, but were not confident in their small rural area, that they could find the right people to employ.

Another family has suggested that where there are no suitable supports in their rural area, allowances need to be made to support short-term accommodation for the person whilst accessing intensive therapy away from home.

Recommendation 11: In rural areas, more flexibility in plans is required to allow for the “thin market” and importantly people with disability and families need to have access to supports and capacity building that will enable them to utilise their communities and to self-managing their packages confidently in these locations.

(m) any other related matters

There is a need to build the capacity of people with disability and their family members to self-manage their funding.

Choice and control are relatively new concepts for many people with disability and their families. Building their skills, confidence and competence is important when considering what is required to change control imbalance that has historically existed and is still apparent today.

Particularly in the case of self-management, a comprehensive guide, workshops, webinars and other supports need to be updated and continued in order to assist a person with disability and their family on how to implement their plan under this arrangement. Support and clear guidance may be needed for budgeting, record keeping, employment of support staff and to outline what type of audit the NDIA might undertake. A dedicated self-management helpline with knowledgeable and competent staff within the NDIA would support this process.

Some people with disability and families have expressed their confusion and lack of understanding of how to use their NDIS plan under the self managing arrangement and fear that they may do something wrong, or be accused of misusing funds. We refer to our discussion about the need for understandable and consistent language (see Recommendation 9). Some participants and nominee's are not using their plan as they feel overwhelmed, do not know where to start and do not have the confidence to do so. This then places them under the very real risk that the unspent funds will be taken away in the next annual review.

Support coordination funding aims to assist with this support for people however we often hear about the inconsistencies in the quality and depth of this role. Improved training and direction for support coordinators as well as more accessible resources as listed above directly available could greatly improve the impact and outcomes for the person with disability.

Irene shared that she has had trouble navigating the system, the price guide is inflexible, difficult to find the right line items and she is getting mixed messaging from the NDIS workshops, the NDIS website and her LAC. She expressed that it would be very helpful for the first few years of the process to have a support person to help her implement the plan so that she could gain the confidence to ensure she was claiming supports correctly as there was a big fear about getting it wrong. Irene commented that her LAC was so busy; she does not have any time to help her.

Recommendation 12: Invest in the promotion of self-management of funding via the capacity building of the person with disability and their family member

The need for a Budget Breakdown sheet

One of our family members, Craig, brought to our attention that he accidentally discovered that a document exists called a “ Budget Breakdown” sheet, which is a detailed sheet containing the hours of support provided and calculation of supports for his son’ s NDIS plan. After discovering this, he requested it from his LAC and received a copy. With this document, Craig was able to work out that the NDIS had made a mistake in their calculations of his son’ s NDIS plan of an overpayment to the tune of $60,000. Craig also was under the impression this Budget Breakdown sheet was readily provided to service providers. This leads us to query, why is it not communicated to the participant that such a helpful document exists, and why does a participant have to request such a document? Much greater transparency is required.

Recommendation 13: A Budget Breakdown sheet be automatically provided to participants along with the draft plan.

Create a toolkit of local resources

A number of families have suggested it would be helpful to provide a community toolkit of local resources, services and community groups that could be accessed prior to the planning meeting. The NDIS has a list of providers across the states grouped in type of business however this does not assist people looking for organisations in their local area. It also does not assist people looking for more typical mainstream community options this could potentially be the work of competent LAC’s with a focus on all community pathways and not just the disability service provider focus.

Recommendation 14: Create a comprehensive toolkit of local resources

Conclusion

This submission has clearly illustrated that people with disability and/or their family member need the NDIS planning process to work effectively and efficiently. As described, when it does not, it creates a tremendous amount of stress and takes away from utilising the funding supports in a way that's beneficial for the person with disability.

The need for advocacy has never been greater. The NDIA must provide the due diligence required to overcome the systemic barriers discussed in this submission.

Clearly, there are many issues with the NDIS planning process that can be improved upon:

- ensure independent disability advocacy is funded by each state and territory government
- NDIA communication to be clear and consistent
- provide a draft plan for all participants
- have planners with a strong understanding of support requirements and contemporary support arrangements
- be person-centred not group centred
- promote, support and understand Self- management arrangements
- provide support in the planning process
- have accessible, transparent, planners with a flexible approach
- be timely in responsive to internal review applications
- provide information of local resources

If these recommendations were implemented, we are confident the number of internal review applications and appeals to the AAT would decline.

There is strong evidence that clear direction and capacity building is needed to ensure that Self-management and the choice and control that is attached, can be successful. This can strengthened by investing in people with disability and their families.

Whilst there have been significant problems brought to our attention, they are not insurmountable as long as the NDIA is prepared to listen to the feedback from people with disability and their families. We hope the Joint Standing Committee on the NDIS will support our recommendations, and that they are implemented by the NDIA.