Submission
No 262

INQUIRY INTO IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND THE PROVISION OF DISABILITY SERVICES IN NEW SOUTH WALES

Organisation: Family Advocacy

Date Received: 9 August 2018

family
ADVOCACY

SUBMISSION

Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales

LEANNE VARGA

Systemic Advocate
Family Advocacy

August 2018

TABLE OF CONTENTS

Terms of Reference

OVERVIEW

Family Advocacy empowers families to advocate 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 on the needs of people with disability, from a family perspective.

Family Advocacy was founded 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 have more choice and control over decisions and supports that facilitate individualised lifestyles for their family member. This includes making the most of emerging opportunities for self-directing supports 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 into this "Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales". We have addressed the areas that are relevant to our experiences in supporting families as the NDIS rolls out, shaped by the accumulated knowledge of families over 28 years of advocating for supports, policies and practices that value the lives of people with disability, as well as by some input from a survey of family members who have a child with a disability accessing the NDIS. 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 for the questions as per the Terms of Reference.

EXECUTIVE SUMMARY

Family Advocacy has made the following key recommendations:

Recommendation 1: The NSW Government commit to ongoing funding for disability advocacy.

Recommendation 2: The NDIA work on cultural change to be genuinely person-centred.

Recommendation 3: That more in-depth training is provided for all staff including LACs, NDIA planners and the 1800 help desk to properly understand the needs of a person with disability and Self-management.

Recommendation 4: That more supports be provided to the person with disability and their family member before an NDIS planning meeting.

Recommendation 5: Invest in the capacity building of the person with disability and their family member to be able to self-manage their funding.

Recommendation 6: That a draft plan is needed to avoid unnecessary reviews and to alleviate any anomalies or misunderstandings.

Recommendation 7: That a Budget Breakdown sheet should automatically be provided to participants.

Recommendation 8: The Planner be accessible to the participant.

Recommendation 9: That plain English, as well as understandable and consistent language be used in all verbal and written communication.

Recommendation 10: The MyPlace portal be more user-friendly with updated technology that makes it more flexible.

Recommendation 11: The NDIA adopts further measures to reduce the time it is taking to process Reviews.

INTRODUCTION

> *The NDIS framework allows for a diversity of activities and supports to be incorporated into the daily life of the person with a disability.*
>
> Trisha, mother of Jordan

This positive view of the NDIS has unfortunately been drowned out by the voices of families that have been overwhelmed with the implementation of the NDIS. Despite the good intentions of the NDIS, many feel " worse off" . They are experiencing a myriad of problems with the implementation of their NDIS plan in providing choice and control, which we discuss in detail below.

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. An overwhelming number of families who responded to our survey feel their NDIS experience has been alienating, time wasting and has created mistrust and disillusionment. This is highlighted the need for independent advocacy to ensure that people with disability have their rights promoted and protected.

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. 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 below with a particular focus on supporting those that elect to self-manage their supports. We ask these recommendations be accepted by the Portfolio Committee No.2 - Health and Community Services and communicated to the NDIA.

TERMS OF REFERENCE

(A) THE IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND ITS SUCCESS OR OTHERWISE IN PROVIDING CHOICE AND CONTROL FOR PEOPLE WITH DISABILITY.

We discuss below the systemic barriers of the NDIS providing choice and control for a person with disability and solutions to making it a success.

The need for advocacy

The introduction of the NDIS has created significant change in the sector and for people with disability. The current problems with the implementation of the NDIS are resulting in a greater need for independent disability advocacy. Our families have expressed shock that so much advocacy is required on their part under the 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 want to be heard 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 fully participate in the NDIS and be included in the community. On a systemic level, no system is perfect. Disability advocacy provides an alarm bell to warn where there are barriers in order that the National Disability Insurance Agency (NDIA) can respond to failures in the system, prevent unnecessary cost, time wasting, and 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." [1]

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 specialists 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."[6] 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.

Once the NSW Government provides long-term funding for disability advocacy, disability advocacy organisations, people with disability and government can work together to make NSW a place where disability doesn' t mean a lifetime of exclusion; where we can spot problems and fix them - tackling abuse and preventing tragedies before they happen.

It' s time to ensure people in NSW will always be able to turn to independent specialists in disability advocacy when they need them.

Family Advocacy calls on Portfolio Committee No.2 - Health and Community Services to make a recommendation to the New South Wales government do the right thing and publicly commit to ongoing funding for disability advocacy, representation and information services for people with disability.

Recommendation 1: The NSW Government commit to ongoing funding for disability advocacy.

The need for a culture shift to be a genuinely person-centred approach

> *The NDIS has delivered on providing more support to people with disability. Even so people with disability remain segregated and isolated from mainstream community. The NDIS promised to transform disability services so that people with disability would have choice and control over their supports with a greater focus on community inclusion. However currently people with disability continue to experience segregation and isolation from the mainstream community. There needs to be greater emphasis and support for inclusion. This is an investment that will assist people with disability to build their social capital and social networks, self-confidence and opportunities to contribute economically, socially and politically as an active and valued citizen.*
>
> Jenny, mother of Kate

The original intent of the NDIS is to be person-centred. However, in practice, the tendency to fund group setting over individual supports is pervasive, reflecting the mindset of a business model. 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 that 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 is a one size fits all approach and does not recognise that some programs do not work in groups, especially when it is about mental health.

Recommendation 2: The NDIA work on cultural change to be genuinely person-centred.

The need for better training for NDIA staff based on values and rights

> *My experience with the NDIS has been poor. Lack of correct information by NDIA, NDIS and LAC staff. Especially for self-managed people. I found the people I first dealt with had no understanding of what families are dealing with but they were the ones with the power not the person with disability. When mistakes were made by NDIS, it took several weeks to change them while the family was left to deal with the best they could. It was an extremely stressful experience and remains so when dealing with the NDIS*
>
> Martin, father of Felix

There is strong feedback from families that there is a large vacuum of knowledge about self-management on the part of LACs and planners. One LAC told a family member that she should not self-manage as it was too complicated and meant she had to get insurance. One 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 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 NDIS has been rolled out too fast. This has meant that the NDIA has employed and/or subcontracted work to planners and Local Area Coordinators (LAC's) without ensuring that those people have sufficient understanding of the needs of people with disability. In addition, there has been insufficient attention to the proper training of Local Area Coordinators. The link between the Planner (i.e. the decision-maker) and the person with disability appears indirect and weak.*
>
> *Our son's first plan more than met his needs, so we were expecting there to be a drop in the amount of funding attached to his second plan. However, when our son's NDIS plan was reviewed after the first year, the plan only gave him approximately half of the funding he required to meet his needs and to sustain the supports that had already been set in place. The LAC was most surprised to learn this outcome, as it did not reflect the LAC's view of our son's support needs.*
>
> *This was a very distressing time for us. The NGO that supplied most of his staffing would only put a contract in place for 6 months.*
>
> *When we first asked for a review of the plan, our request was rejected. However, after gathering further documentation and 'painting a picture' of our son's background and day-to-day life, and using the complaints process, he received increased funding following a review. This was very time-consuming and emotionally exhausting, especially when we discovered that the NDIS had*

> *not passed on the documentation to the key person doing the review. Fortunately, I realised when I was contacted that this was the case and was able to forward the documentation directly to her.*
>
> Billy, father of Rhys

The above example not only illustrates the added administrative burden, and stress being placed on families that are already working hard to create good lives for their person with disability but also that LACs/planners are not in touch with the support needs of the person with disability. More depth and breadth in training is required from those with experience based on the social model of disability, have a deep understanding of what makes an ordinary life with socially valued roles, and have knowledge of the UNCRPD (United Nations Convention on the Rights of People with Disability).

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.

Recommendation 3: *That more in-depth training is provided for all staff including LACs, NDIA planners and the 1800 help desk to properly understand the needs of a person with disability and Self-management.*

The need for supports before NDIS plan meeting

Good quality pre-planning support is required. There is still 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 clearer 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 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, for example, go to Scouts, 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.

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 energetically and emotionally. This goes against what the NDIS was intended to achieve.

To provide support in pre-planning, one suggestion 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.

We acknowledge that support coordination within self-management has now been approved, however, this needs to be communicated properly to those that self-manage, to the NDIA staff and to the wider community.

Recommendation 4: That more supports be provided to the person with disability and their family member before an NDIS planning meeting.

The 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 people with disability and their parents or carers. Many families do not know how to actually take control and do not really understand what it means. Building their skills, confidence and competence is important when changing the control structure. Even for family members who are competent to exercise choice and control, there is not enough knowledge about the NDIS.

Particularly in the case of self-management, a comprehensive guide, workshops, webinars and other supports need to be in place to teach a person with disability and their family how to implement their plan. Support and clear guidance may be needed for budgeting, record keeping, outline what type of audit the NDIA might undertake. A dedicated self-management helpline with competent staff would be helpful.

> *"It would be good if easily accessible workshops could be run by NDIS for self-managed people that were very simple that included legal requirements of accounting, tax, wages, bookkeeping and staff."*
>
> Geoff

Some families have expressed their confusion and lack of understanding of how to use their NDIS plan 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 families 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.

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 5: Invest in the capacity building of the person with disability and their family member to be able to self-manage their funding.

The need for a draft plan

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?

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.

Recommendation 6: *That a draft plan is needed to avoid unnecessary reviews and to alleviate any anomalies or misunderstandings.*

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 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 7: *That a Budget Breakdown sheet should automatically be provided to participants.*

The need for accessibility to the NDIS Planner

The link between the Planner (the decision-maker) and the person with disability appears indirect and weak. The lack of transparency and power imbalance between the participant and the Planner is a problem. The Planner has the power to determine the quality of the participant's life for the next 12 months or until a review of the Plan. The Planner has unlimited access to all of the participants' personal 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.

On the flipside, a planner is a faceless person with a lot of power that is not accessible to the participant. It seems that no participant is given any information about their planner - no email, no phone number, not even their surname is provided. After a participant receives their plan, they cannot contact the planner directly to ask any question to understand how they came to the decision or to clarify a mistake or query the plan in any way.

Due to these communication barriers with the Planner, there appears to be a lot of time wasting and unnecessary reviews and frustration for families. Often, if there is an issue with their NDIS plan, the family will approach the LAC, who will suggest they apply for a review of a reviewable decision. This adds a further burden to families who are required to do more paperwork, and take more of their time to obtain more reports and prepare a review. The intention of the NDIS being person-centred is not being practiced here.

If the participant met their planner face to face, the hope is that they would have a far greater picture of the participant and better understand the support needs of the participant. This should ultimately lead to a better quality plan and far fewer applications for plans to be reviewed and therefore, cost the NDIA less in resources.

Recommendation 8: The Planner be accessible to the participant.

The need for Plans to be in Plain English with understandable and consistent language

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 and there are no explanations supplied.

> *The NDIA need to make the language of the NDIS understandable and consistent. Currently, the language describing support in plans differs from the language in the portal. Neither are self-explanatory. What is called Core Supports in the NDIS Plan comes up as Daily Activities in the Portal. Similarly, Improved daily living in the plan comes up as CB Daily; Finding and Keeping a Job comes up as CB Employment. Also, if more information is needed to determine funding, the NDIA should ask for it. This could avoid unnecessary reviews.*
>
> *Linda, mother of Nathaniel*

Linda is a native to the English language, is educated, well resourced and knowledgeable about the NDIS. If English-speaking families are having trouble understanding the plan, 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 the Agency provided clear and consistent written communication in relation to what services can be utilised in each of the categories, with clear definitions and in the case of being declined certain supports, a proper explanation as to why.

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

The need to improve the Portal

We have several issues reported regarding the MyPlace portal.

One family member reported that she could not access the portal for her son for the last 6 weeks. Each of the six (6) times she called the NDIS 1800 number, she was given different and conflicting information. Sometimes the wait to speak to someone can be for up to an hour. First, she could not access his MyGov account being told she had to go through her own MyGov account. Then she was told she needed her own NDIS number even though she is not a participant. Next, she was told it could not be in her name as the funding was in her son' s name. The last time she spoke to them, they told her that the last person gave her the incorrect information, that it was an issue with the finance department and she would have to wait another 2 weeks before she could access the portal.

This family member expressed her frustration with a system that the NDIS enforced upon her " all responsibility and no control" . She wanted to be able to speak to the person who had the capacity to fix her problem such as the technical person in the self-management section but instead; she spoke to a nameless, faceless person who was different each time. She made a complaint over a year ago and did not hear anything back yet she has to jump through hoops every time she wants to resolve an issue. She mentioned that her NDIS experience was soul destroying.

The above example illustrates that even if a family member representing a person with disability is trying to exercise choice and control, their attempts are stymied by technological and administrative problems with the NDIA.

Recommendation 10: *The MyPlace portal be more user-friendly with updated technology that makes it more flexible.*

The need to reduce the time delays for Reviews

Despite the NDIA' s attempts at addressing the backlog of Reviews, many families contact us for assistance due to lengthy review periods. We recently received a call from Katarina, who was still waiting for her " review of a reviewable decision" to be heard after nine (9) months. This is not acceptable. Her attempts to contact the NDIA hotline have not been helpful. She was very upset because she had to say goodbye to her physiotherapist, whom she had been seeing for years for therapy, due to her funds running out. Ironically, this is the reason why she applied for the review.

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 to six (3-6) 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.

As an aside, in relation to the Review form online, it only comes in PDF form, not Microsoft Word. For a person with disability, it makes it inaccessible to be able to print, read, write, scan or post the form, thereby creating another barrier. It would be helpful to provide the Review form in Microsoft Word format as well, as is done with all other forms.

Should the NDIA adopt our recommendations, we are hopeful that this would mean that the number of Review applications would decline also.

Recommendation 11: *The NDIA adopts further measures to reduce the time it is taking to process reviews.*

(B) THE EXPERIENCE OF PEOPLE WITH COMPLEX CARE AND SUPPORT NEEDS IN DEVELOPING, ENACTING AND REVIEWING NDIS PLANS.

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 with great opportunities for James 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 given the power over what are the most optimal support arrangements for their person with disability. The NDIS needs to remain flexible to allow for the fact that one size does not fit all and to allow for thinking outside the square. This would also assist families in rural or remote areas where options are limited.

The other important point to note here is that James' situation only worked well because he has a family member advocating for him. His father is an educated, competent, connected and confident individual. We are concerned for those who do not have a competent family representative. We strongly doubt that any service provider, with profit as their primary motive, would provide anything other than a cookie cutter approach. Where a service provider is not providing an adequate service to a person with complex needs, or where they decide to not provide them with a service at all, there is no safety net.

(D) THE EFFECTIVENESS AND IMPACT OF PRIVATISING GOVERNMENT-RUN DISABILITY SERVICES.

We are concerned that with privatising government-run disability services, where profit is the primary motive and the grouping mentality presides, there is no safety net for those people with disability who fall through the cracks. We are concerned for those with complex needs who do not have a strong advocate in their corner, who are not being well serviced or dropped by the service provider. It is important that there be some oversight and investigation as to where these gaps exist.

(E) THE PROVISION OF SUPPORT SERVICES, INCLUDING ACCOMODATION SERVICES, FOR PEOPLE WITH DISABILITY REGARDLESS OF WHETHER THEY ARE ELIGIBLE OR INELIGIBLE TO PARTICIPATE IN THE NATIONAL DISABILITY INSURANCE SCHEME.

The NSW government needs to be proactive to ensure support services are available for those that are ineligible for the NDIS. There will always be people with disability who need supports, and advocacy to assist them to access services.

The NDIS Supported Independent Living (SIL) funding process is highly flawed and presumes all people with disability will live in group homes. Completely negating individual choices in living arrangement, the SIL process funds people with disability on "capacity to share". A more nuanced approach is required to support individualised housing, more scope in sharing with flatmates that do not have a disability.

Previously, under the old ADHC system, in the case of a dual diagnosis of disability and mental health the NSW government funded a psychologist practice to provide a person with disability to have psychological or psychiatric care. Under NDIS, this service is no longer funded. A person with a lifelong intellectual disability who has developed a mental health issue should be given support for this.

(F) THE ADEQUACY OF CURRENT REGULATIONS AND OVERSIGHT MECHANISMS IN RELATION TO DISABILITY SERVICE PROVIDERS.

> *The new NDIS Quality and Safeguard Commission is designed to be assisting with improving quality and safeguard. It remains to be seen whether old practices of denying human rights continues.*
>
> George, brother of Anastasia

We are pleased there are more avenues for a person with disability to go to make a service provider more accountable than they were under the old system - Code of Conduct, NDIS Quality and Safeguard Commission, Department of Fair Trading, Administrative Appeals Tribunal. We are hopeful that the presence of these avenues will provide adequate safeguards however, we have not received any feedback to date to be able to comment.

(G) WORKFORCE ISSUES IMPACTING ON THE DELIVERY OF DISABILITY SERVICES.

We do not advocate for standardisation or qualifications being placed on support workers. However, we do recommend the NDIS supports the training of support workers where relevant, particularly in the case of a person with disability with complex need.

From a self-management perspective, flexibility in the workforce is important. For example, Kathryn, who manages the staff for her sister, Margaret, deliberately does not employ people with any disability certificates but rather considers the appropriate support worker to be a person of good character, patient, would listen and talk to her sister, be able to cook, have housekeeping skills and also have the same interests/hobbies as her sister. In the past, Kathryn found the traditional disability support worker would try to turn her sister’ s home into a workplace rather than respect that it was her sister’ s home. There is a big cultural difference to the staff in this regard as there is a values-based attitude in line with the social model of disability as opposed to the medical model.

We appreciate that there may be more limitations in rural and remote areas but this approach might be a way of solving the lack of traditional workforce supply. Of course, given this is a new way of thinking about supports, it would be important to communicate and support people with disability and their family member on how to go about doing so.

(I) INCIDENTS WHERE INADEQUATE DISABILITY SUPPORTS RESULT IN GREATER STRAIN ON OTHER COMMUNITY SERVICES, SUCH AS JUSTICE AND HEALTH SERVICES.

One area that is problematic, shared by a family member, relates to the removal of mealtime planning supports by speech therapists from NDIS to health. The most common cause of death of people in support accommodation is aspiration related illness (such as pneumonia) and or choking (NSW Ombudsman disability death review each year). These are preventable deaths. A speech pathologist or dietitian can provide advice regarding peg feeding or if food is required to be cut up into a particular size for safety reasons, or with overeating/under-eating issues.

The NDIA has determined that mealtime planning is a health issue and currently will not allow speech pathologists or dietitians to claim mealtime assessments and strategies from NDIS funding. Unfortunately, NSW health provides little support in this regard either. It is our understanding that there is a standoff between NSW Health and NDIS on this issue. Considering lives are at stake, this situation is abysmal.

There are many other grey areas between NDIS and health. The NDIS needs to be actively engaged in discussion and reporting on the interface with mainstream services around service gaps, duplications and boundary issues through the relevant COAG Councils. It is essential that clarity be provided where there are "grey areas" so that the person with disability is not disadvantaged.

(J) POLICIES, REGULATION OR OVERSIGHT MECHANISMS THAT COULD IMPROVE THE PROVISION AND ACCESSIBILITY OF DISABILITY SERVICES ACROSS NEW SOUTH WALES.

> *They need people who are experts on Self-management and how to navigate the system. The lack of correct information and knowledge by NDIS personnel is extremely frustrating. People are reluctant to take this way because it's complicated. Applying for funds through the portal is not user friendly because of the number of screens you have to go through to make sure you're using the right bundle of funding. If you have a problem you cannot talk directly to anybody that can deal with it. I think it would work much better if I dealt directly with a planner than going through LAC then a planner on the annual review. I find that answering the same questions I did the year before annoying and time consuming and it would be more beneficial to talk about my daughters needs specificity. I don't feel my daughter and I have any power but are at the mercy of strangers that insist on coming into my home to assess us. This is my feeling and not fact, however, the system of collecting information and processing it is extremely stressful for us that live in it.*
>
> Tonia, mother of Cynthia

The NDIA need s to provide more competent personnel, be more transparent, more accessible, and more consistent.

(K) ANY OTHER RELATED MATTER.

Firstly, there has been an issue raised by several family members that there needs to be more flexibility regardless of the form of management they choose, be it Self-managed, Agency managed, or Plan managed.

> *There are times when we would like to send a support person to external training which would benefit my son; however as my son is Plan Managed, unfortunately, his NDIS funding can not be used for this purpose.*
>
> Kathryn, mother of Simon

> *System needs to change and be more flexible for people with disability so that there are no barriers, challenges or limitations put in front of them stopping them from being able to use their funding flexibly and freely to their interests without the service providers saying to the person with disability what you can and cannot use your funding for. This applied to me when I wanted to study a Certificate IV in Training and Assessment at TAFE and was told by my plan manager that I cannot have this paid for by the NDIS even though this previously funded under the state system.*
>
> *Sarah*

Another family member who is Plan managed has expressed the limitations when it comes to choice and control over support staff pricing and arrangements. She is also concerned that the service provider is charging the highest rate on the price guide for young University students that are untrained/ unskilled staff.

Second, a number of families have requested that the veil is lifted between the artificial distinction between core funding and capacity building and allow flexibility in spending. We refer to the previous case study of James whereby he did not use traditional therapy for behaviour management but rather doing valued roles in his community. He cannot use his capacity building funding as it is not specifically for a therapist but should be able to use it to fund the support workers that assist him in his daily rounds of voluntary employment which is effectively his behaviour management therapy.

Third, the School Leaver Employment Supports (SLES) could improve the quality of the training. For example, Laura' s SLES training ended five (5) months before the two (2) year period that the service provider was being paid for, she was given little support once she commenced employment, and was not taught how to fill out forms such as tax declaration forms, about workers rights such as having breaks, and workplace bullying and harassment. Laura' s mother has been left to fill in all the gaps that should have been provided by the service provider.

In addition, communication must improve between departments and agencies of the NDIA as people with disability are being disadvantaged. In Laura' s case, even though the SLES training was cut short, and she is working, she is unable to gain access to a mobility allowance which she is entitled to, because the system shows that she is on the SLES program for another five (5) months.

CONCLUSION

From the information provided by families supporting a person with disability, it is clear there are many issues with the implementation of the NDIS providing choice and control. Families have experienced poor communication, lack of genuine understanding of support requirements and Self-management, lack of support in the planning process and the implementation of Self-management, lack of accessibility, transparency and flexibility.

There is a strong sense that clear direction and capacity building would be needed to ensure that Self-management and the choice and control that is attached, can be successful. This can clearly be accomplished by investing in families and respecting a family' s perspective on their person with disability whilst considering the normative pathways that are currently available. Self-managed families need to be properly supported by NDIA policies, its staff and agents, the NDIS system, and the Portal.

Each family has its own method of operating and each person with disability in their life has their own support needs that need to be considered. The family is best placed to make these decisions as they are for their other children without disability and any system changes should have this at the cornerstone of its design.

The above feedback highlights there is a fine balance between choice and control and the extra work that this entails. The need for advocacy has never been greater. Family Advocacy wants the NDIS and particularly Self-management to be a success so a person with disability can live a decent life being included in their community. The NDIA must provide the due diligence required to overcome the systemic barriers discussed.

Whilst there have been significant problems, they are not insurmountable as long as the NDIA is prepared to listen to the feedback from families. We hope the Portfolio Committee No. 2 - Health and Community Services concur with our recommendations, communicate these to the NDIA and that they are adopted by the NDIA.