Submission
No 115

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

Organisation: Autism Advisory and Support Service
Date Received: 26 July 2018

DISCUSSION PAPER.
NDIS CURRENT ISSUES AND RECOMMENDATIONS.

AUTISM ADVISORY AND SUPPORT SERVICE
88 MEMORIAL AVE LIVERPOOL NSW 2170
WWW.AASS.ORG.AU
JULY 2018

Autism Advisory and Support Service (AASS) are a grass roots not for profit community organization who support families on a daily basis through the journey of having a child with disabilities, especially an Autism Spectrum Disorder. We also offer a multi disciplinary approach to therapies and supports for each individual, depending on their needs and those of the family. This is in line with the true spirit of the NDIS. Choice and Control.

While in theory the NDIS is a wonderful scheme that has supported many, the reality in our area of Liverpool and surrounding local government areas, is quite different.

AASS, through the families we support and serve, have experienced a number of issues and anomalies. Each NDIS experience and funding plan is subjective. If one has a planner who understands and listens to each experience, then the outcomes are more favorable than those who have planners who need to Google the disability during the planning meeting. We have also experienced a number of administrative issues that are frustrating and time consuming.

AASS are passionate about the welfare of the families we serve. This paper reflects the reality of the NDIS experience of most of our participants. We have put together a few ideas on how the current NDIS system can be tweaked to strengthen foundations so children and adults can realize their individual potentials and lead independent lives outside of the welfare system.

Grace Fava

Founder/CEO

The NDIS was introduced to

- "provide all Australians under the age of 65 who have a permanent and significant disability with the reasonable and necessary supports they need to enjoy an ordinary life"
- "help people with disability achieve their goals. This may include greater independence, community involvement, employment and improved wellbeing."
- "an insurance scheme, the NDIS takes a lifetime approach, investing in people with disability early to improve their outcomes later in life."
- "provide people with disability, their family and carers with information and referrals to existing support services in the community."

Issue	Recommendation
Limited workforce. Since the introduction of NDIS, many senior and experienced therapists have found there is more money to be made in working as a standalone practice than working for an organization. This has created a void in the sector for senior and experienced therapists, in particular in the field of Occupational Therapy. There is also a lack of experienced, capable support workers. Most workers in the field of disability support seem to be individuals with limited English and no experience in the sector.	✓ Engagement/recruitment drive in schools and Universities to discuss the benefits of a career in allied health. ✓ Retraining workers faced with redundancy. ✓ Any worker engaged in disability support work MUST be accredited and have experience before starting in the role.
No Choice and Control in plans. Currently all plans are funded to an unofficial cap. Each cluster of funds are dictated and are not flexible in the plan. If a participant requires more funds in one category they must apply for a change of circumstance/request for unscheduled review which will take in excess of six months in many offices.	✓ Allow funds in each plan to be flexible between categories without the need for a lengthy review.

Autism Level 1 and 2 Currently Autism level 1 is not given immediate access to the NDIS and level 2 is now under scrutiny by an "expert panel". According to the NDIS fact sheet: *"The NDIS will provide all Australians under the age of 65 who have a permanent and significant disability with the reasonable and necessary supports they need to enjoy an ordinary life. The NDIS will help people with disability achieve their goals. This may include greater independence, community involvement, employment and improved wellbeing."* Individuals with levels 1 and 2 Autism are capable of achieving independence with the correct and meaningful supports. These participants are the ones for whom the NDIS can help to live independent lives contributing to society and not depending on welfare. Yet we are focusing on this group as they are one of the largest to require support.	✓ All levels of Autism to receive NDIS to support their needs ✓ Better training for planners to identify needs and areas for support ✓ Better support around transition to the workforce, social skills, sensory needs and communication to empower participants with the tools to be independent members of society.
No clarity around NDIS guidelines. Presently the guidelines are subjective at best and unclear at worst. Any advice requested by NDIS workers will never be issued in writing and is to be taken at our own risk. Participants and organizations cannot wait for the Appeals tribunal to issue a decision. There is a disparity around Australia with plans, understanding of phrases such as "reasonable and necessary" and even basic understanding by planners of various disabilities and the level of need required by participants.	✓ Clear policy around what can and cannot be funded ✓ Specific and clear policy and/or guidelines that stipulates what is required for the participant. This needs to address the necessary supports for individuals with a physical disability as well the complex and varying needs for those with invisible disabilities who often have comorbid diagnoses.
Untrained Planners. Many planners and local area coordinators (LAC) have no experience in disabilities. They are unfamiliar with the lived experience of participants and have been known to google the disability in a planning meeting.	✓ Meaningful and extensive training for planners and LAC workers in disabilities and how they impact on participants and their families. ✓ Professional development annually for planners and LAC workers. ✓ Planners to have a current disability qualification – at minimum a certificate IV in disability or community services.

	✓ Planners to have proficient literacy skills to understand reports and relay this information.
Waiting times to access NDIS. Many families have to wait in excess of 3 to 6 months to enter the NDIS. They are left with a few Medicare items to try and commence therapy. Many organizations will not accept a participant without an NDIS plan.	✓ If a participant has an official diagnosis that meets NDIS access criteria, they should be allowed immediate funding and support. This should take no longer than 6 weeks from time of application approval. ✓ Introduce a tiered system of funding for straight forward participants who have an invisible disability. EG Level 1 Autism $15,000 Level 2 Autism $25,000 Level 3 Autism $45,000 These funds can be spent on therapies, incontinence products and accessing community and other social programs. This will reduce the need for a planner and for frustration for families. **If these amounts are not sufficient then the participant can request a planning meeting.**
Waiting times to access Early Child Early Intervention (ECEI (funding) Current wait times in south west Sydney for ECEI are in excess of 12 months. Families are left with a few Medicare items to try and commence therapy. Many organizations will not accept a participant without an NDIS plan. A new ECEI provider was introduced as at 1.7.18. They are not prepared for the backlog of plans nor the calls from new participants. ECEI waiting times significantly impact the Education system in a negative way. Children with additional needs require early intervention therapy to prepare them for school. These waiting times are unacceptable.	✓ Approved ECEI participants should receive a package of $5,000 to start early intervention treatment. In the spirit of HCWA this amount will be a stop gap until their planning meeting.

Unofficial caps in funding of plans and cuts from one plan to the next. There are obvious caps in funding for participants. This is despite their needs for supports. (See E Nashmi plan) Plans are cut in half from one plan to the next, even with professional reports stating that the current levels of support are achieving goals.	✓ Offer a capped plan (see solution above) to save parents from the addition stress of attending planning meetings. This will save money as it will decrease the need for planners. ✓ Planners to read reports and adhere to the professional recommendations.
Uncertainty around funding of supports for Children in the care of the Minister. Participants under the care of the Minister (out of home care) are caught in a financial tug of war between NDIS and FACS as to which department is financially responsible to fund items of need.	✓ Clear policy on financial responsibility for out of home care children. ✓ Clear guidance on what the NDIS will fund and what FACS/Agencies are responsible to pay.
Access questions for Participants with an Invisible disability. Current NDIS questions that form the basis of an NDIS plan are aimed at participants with a physical disability. They are yes or no questions which in many cases for those with an invisible disability such as an Intellectual Delay or Autism, do not apply.	✓ A new set of questions that are directed to participants with an Invisible disability to ensure meaningful and relevant information is gathered.
No current safety net for families in crisis. Currently there are no safety nets for families who cannot cope with children presenting with escalating violent and aggressive behaviours. For those who call an ambulance, they are given a sedative and by the time they reach the hospital, they are calmer and are told to go home. For those with no informal supports they are faced with nowhere to turn. A single mother rang us on a Saturday to relinquish care (there was no other number to call). We contacted the respite centre the child attends and they said they could not help at all. After contacting more than a dozen organizations we finally found a provider to offer emergency accommodation. This process took two weeks. This child self harms to the point of requiring hospitalization.	✓ A line that families in crisis can call that will offer immediate and effective support for children at risk of relinquishment. ✓ A specialized centre that is staffed with 24/7 care for participants like this one who are trained in supporting individuals with profound disabilities.

Disparity between plans and NDIS offices, and planners. There is a lack of consistency in plans and funding. While each participant is unique with their own needs and family situations, we have cases where identical twins with the same needs and diagnosis had different planners and as a result, vastly different funding.	✓ Where more than one person in a family are eligible for NDIS funding, they should always have one planner who can take in the needs of the family and ensure equal and meaningful funds are allocated. ✓ To ensure plans are less subjective, introduce tiered funding for levels of disability.
Assistive Technology (AT) requests. In order to access AT, the planner currently approves this. The participant then has to reapply with a quote and wait for approval, even though there is an amount granted in the plan. We have participants who are currently waiting in excess of 12 months for communication devices that will give them a voice.	✓ Once Assistive Technology (AT) has been approved at the planning stage there should be no need to reapply for quote approval. Each plan with AT has already been funded with a cap. The participant should be allowed to purchase from the plan. This will free up planner time to focus on other participants.
Lack of funded services in South West Sydney to support with plan reviews, changes in circumstances and basic support. South west Sydney is growing in population with young families finding more affordable housing options there. There is a great influx of immigrants with young families, in particular from middle eastern backgrounds where cultural practices (marrying in the family) produce children with chromosomal disorders and other disabilities. It houses one of the largest culturally and diverse populations in the country and one of the lowest socio economic populations in the state. Yet with all of these issues there are long waiting lists for services, no funding for support coordination and no basic supports to guide families through the maze of the NDIS. The LAC's are not able to offer meaningful support and often do not return calls from families in need. **AASS are inundated with calls from Medical professionals, schools and even NDIS workers to support these families.**	✓ Fund more organizations in south west Sydney to support families in these areas. ✓ Recruitment drive for more support workers.

Lack of support coordination funded for families in need. Support Coordination was established to support parents and carers from non English speaking backgrounds and those with additional needs to navigate the NDIS and establish meaningful supports for the participant. AASS have discovered many parents and carers who have not been funded for support coordination who live in south west Sydney. These families are/have: • refugees, victims of domestic violence, single parents and individuals who have a mental health issue. • Have no support system in Australia • Low or no level of computer literacy, some do not even own a computer, lack of access to the portal • At risk of exploitation from providers, seeking to access all of the NDIS funding from the participants plan • Shame and embarrassment when they realise that the funding is gone. Unwilling to complain for fear of retribution • Low/limited English, no funds in plans for interpreters • CALD families require an initial intense level of support to build capacity and confidence • A cultural lack of trust of government agencies LAC's do not have time for plan implementation or experience. AASS frequently receive calls from NDIS and LAC offices for advice and/or to manage complex cases	✓ Funding for support coordination to families who fit the criteria to build vulnerable families capacity and knowledge, so that they can effectively manage their loved one's funding. ✓ Planners and LAC's to have training to recognize families requiring support coordination. ✓ Funding for interpreting services where required ✓ Access to the portal in a format other than online. ✓ Fund more organizations in south west Sydney to support these families.

The establishment of the Advisory Group reflects the NDIA's commitment to working with key stakeholders and experts who support people with autism. *According to correspondence from a Member of Parliament:* *Among the issues the Advisory Group will be asked to discuss are:* • *The increased prevalence of autism within the Australian population, as reported by the Australian Bureau of Statistics;* • ***The work, funded by the NDIA, but undertaken independently by the Autism CRC to develop a set of best-practice diagnostic guidelines. This work has been submitted to the National Health and Medical Research Council for review;*** • *The relevance of the new PEDI-CAT (ASD) as a functional assessment tool in the Australian context;* • *The NDIA's proposal, as part of its Participant Pathway work, for an independent third party to undertake a pilot to assess which functional assessment tools are most appropriate to assist making eligibility assessments for the NDIS. There will be no cost to individual's seeking access to the scheme from the proposed pilot;* • *Whether functional assessment tools can assist with defining the necessary supports for participants to have a better life;* • *The best approach to delivering autism services for eligible NDIS participants and children who receive ECEI services, within the context of broader mainstream autism services.* *The NDIA is committed to ensuring the NDIS is equitable, outcomes focused and, in the interests of all participants,* ***financially sustainable****.*	✓ Many of the groups on the advisory group were represented when the DSM-V was released. The issue of Autism diagnosis was already discussed here and agreed to so there is a general approach to diagnosing and understanding of the disorder. Why reinvent the wheel?? ✓ Communication with other Government departments such as Social Services, Department of Education and Health who are already collecting data on Autism. ✓ Speak with grass roots organizations who speak to participants and fully understand their frustrations and needs.

With the prevalence of Autism increasing exponentially why were none of these issues discussed prior to the NDIS roll out? It seems the issue is financial sustainability which is common sense, yet the disparity is nonsensical. Families living in areas like south west Sydney have multiple layers of complexity in accessing the NDIS.	
Access to Plans on Portal is of limited use to providers (goals only). Providers need access to knowledge of plan, such as how funds are managed (agency/self/plan), the breakup of funding allocation and the amount of funding available in different categories.	✓ Where participant grants permission (during the planning meetings or directly to NDIS), more relevant information should be available to be viewed by provider on the portal.
Plans end before the plan end date with no notification to providers. This ends our service bookings prematurely and causes additional administration when our claims are rejected. If the new plan does not cover existing services that are in place, providers risk not being paid for services that they had agreed to with the participant under the old plan.	✓ Start new plans at the due date for the end of the old plan where possible. ✓ All agency changes made to a provider's service booking should be notified to the service provider (either via automated email to provider or a message in the portal).
No communication around tracking a plan. Where a plan is due for its annual review or an unscheduled review is submitted, providers and participants are not kept informed of the progress. Many participants and their providers subsequently contact the NDIS to find out where the review is and how long it will be till it is finalized. This causes much work for NDIS as well as participants and the providers who assist them.	✓ Access to tracking information via the portal would be helpful and save the agency a lot of phone calls.
NDIS plans for CALD participants are difficult to understand. Most participants from a CALD background do not understand their plans nor all of their options regarding the NDIS.	✓ Issue plan in relevant language ✓ Fund a translator in the plan along with support coordination to ensure participants and families fully understand then plan.

Changes in Behavior Support under the quality safeguarding framework. All behavior support practitioners are expected to source behavior implementers with no additional funding. This is not financially sustainable and the sector will be left with a larger gap in this support category as current providers refuse to work within this category. Currently in south west Sydney there are only 4 service providers offering this service. Waiting lists are long for each organization (in excess of 8 months) If a participant accesses supports by a service provider, and that participant has a behavior support plan with a restrictive practice, all service providers to the participant MUST report to the NDIS monthly to the quality safeguard. This reporting is not funded in the participants plan.	✓ More therapists trained in writing and implementing behavior support plans, in particular for complex participants. ✓ Better awareness in Universities for this sector with a minimum of 36 months practical work. ✓ Awaiting matrix and pricing enquiry
NDIS Telephone assistance – staff are inconsistent in their advice and the information they will divulge in relation to participants. Service providers rarely are able to resolve an issue on the phone. There seems to be inconsistent notes placed on participant files when providers call NDIS to action or expedite reviews or other issues on behalf of the client. At times there is no record kept of issues reported. Some NDIS staff are reluctant to give their names and will not issue call reference numbers. There appears to be a lack of accountability in this regard.	✓ Regular and consistent training for staff on the phones to resolve issues at the time of the call. ✓ Clear guidelines for NDIS staff as to what information they can or can't share with providers and make providers aware of this as well. ✓ Issue reference numbers for calls.
Provider Payments emails for assistance in making changes to existing service bookings are incredibly slow and unresponsive. We have average wait times of up to 4 weeks, and that is when we send reminders to chase a response. This provides an unreasonable burden on service providers administering the NDIS.	✓ Allow providers to make changes to their own service bookings on the Provider Portal. These changes would include changes to booking dates and booking amounts. ✓ Allow call centre staff the ability to make these changes.

NDIS slow response to change of circumstances. The NDIS can take an extraordinary amount of time to respond to “change of circumstance” funding requests or funding requests outside of the plan. We have two such claims outstanding since September/October 2017 and cannot get a single reply to our many emails chasing the issues. One participant was suicidal. A change of circumstance form was submitted to the NDIS for emergency access to a psychiatrist. This took three months and many calls to the NDIS to action.	✓ NDIS to have a section for emergency calls (see safety net issue) ✓ Reference number to be issued for ease and efficiency of follow up.
Portal limitations. The portal only allows manual claiming up to 90 days after the service is rendered. However due to the delay in the Provider Payments Team correcting changes in service bookings, by the time it is fixed we can no longer claim and then have to email Provider Payments again to make the claim for us. We have been waiting since 27/4/18 to fix a service booking on the portal and we finally had it fixed on 29/6/18, but we are now unable to claim it and will need to ask NDIS to manually process the claim for us.	✓ Extend the amount of time that providers can claim on the portal manually to at least 6 months, or longer if the Provider Payments team does not respond in a timely manner.
Travel for therapy services is not funded in the NDIS plans. NDIS providers are able to charge up to 20 minutes for offsite therapy sessions. Part of offering a person centred approach to service, we offer the choice of therapy as centre based therapy or in the natural environment. Travelling to the natural environment means travel charges will eat in to an already poorly funded plan.	✓ Fund travel for therapy services where the client identifies the service is provided in the natural environment. ✓ Ensure travel funding is separated from therapy funding.
Support Coordination Bookings made by Agency Staff are not notified to service providers	✓ All agency created service booking should be notified to the service provider (either via automated email to provider or a message in the portal).