

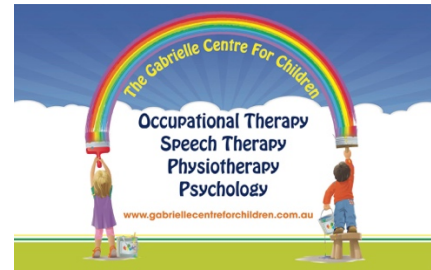
**Submission  
No 268**

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

**Organisation:** The Gabrielle Centre for Children

**Date Received:** 9 August 2018

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9<sup>th</sup> August 2018

Submission for Inquiry into the Implementation of the National Disability Insurance Scheme and the Provision of Disability Services in NSW.

Submission prepared by Natalie Smith, Accredited Social Worker (AASW #464169) on behalf of The Gabrielle Centre for Children (9 Normic Avenue, East Blaxland, 2774). The Gabrielle Centre for Children has been a registered provider of NDIS services since 2015 and provides a number of services, including Early Childhood Supports, Therapeutic Supports and Support Coordination to children in the Nepean/Blue Mountains region. The Gabrielle Centre for Children is a mid-sized consortium offering Speech Pathology, Occupational Therapy, Psychology, Social Work, Keyworker Supports and Music Therapy in both individual and small group sessions.

### **(a) the implementation of the NDIS and it's success or otherwise in providing choice and control for people with disability**

While the NDIS allows for choice and control of providers by a participant, the ability of the individual to exercise this choice and control over their life and the implementation of their plan is limited by the following:

**-Support budgets-** budgets are increasingly being reduced on review to an amount that forces participants to sacrifice vital supports. This is despite ample evidence being provided by way of progress reports and diagnostic evidence demonstrating progress and ongoing needs.

**-Plan limitations-** Plans are increasingly only providing a very limited Capacity Building budget for children with Core Supports being abolished in a majority of cases where they have been included previously. While individuals have choice of providers, plans that lack other Support Categories (e.g. Social and Community Participation) offer little choice for individuals to exercise choice and control over how they implement their plan outside of a therapeutic setting. The inability to transfer funding across budgets also limits choice and control.

Example, a participant has more funding than they need for their chosen therapies in their Capacity Building budget, and wishes to practise using their newly learned skills in the community (e.g. going to the shops which allows them to practice crossing the road safely, waiting calmly in lines, following a visual shopping list, using their communication device to communicate with retail staff and using early money skills). Due to their very high support needs, they require a Disability Support Worker to do this safely and to give them the 1:1

support that they need. Unless they have enough (or any) funding in their Core budget this is not possible and they cannot transfer the excess Capacity Building funding to use in this way.

**-Wait times for Internal and Unscheduled Plan Reviews-** There is currently no way to alter the supports in a plan in a timely fashion should participant needs change (e.g. needing new equipment as a child grows, adding in Core supports in the event of a crisis where family capacity is impacted, including specialised behaviour supports when challenging behaviour puts the individual at risk). The current backlog of unscheduled reviews means that any participant requiring a review is waiting for anything from 6 to 9 months regardless of how urgent their need is, and it is not unusual for their plan not to be reviewed until their scheduled review.

Similarly, when a participant's plan is inadequate and requires internal review there is very little chance of the participant accessing a review of that plan regardless of how urgent the circumstances are. The participant then does not progress as they could, and in many cases regresses which increases costs to the scheme in the long term as their support needs increase.

**-Limited knowledge and information about services, what they do and how to access them.** Participants are generally given a plan and sent on their way, perhaps with a list of services (often out of date) provided by their LAC. Support Coordination is rarely included in plans, and in a significant number of cases participants and families do not understand what the support categories mean, or how to navigate the implementation of the plan. LAC's do not have the time or training to provide this service and are doing so poorly as a result which is resulting in large portions of plans going unused and participants not knowing what is available to them.

**-Incorrect/Misleading Information-** Many families with young children have also been told by Early Childhood Early Intervention partners that they must use the affiliate service of the ECEI, or have signed service agreements believing that this was how to access the plan, only to find the bulk of their funding allocated to that service without having had the opportunity to explore their options. Other misinformation includes planners/LAC's/ECEI's incorrectly telling participants and families that services such as Music Therapy or Social Work are not covered by NDIS funding.

**-Inadequate or Poorly Written Goals-** Participants will often express what they would like their goals to be. These goals are often ignored or altered by the LAC or Planner, even in cases where the participant has specifically written and submitted the goals that they have chosen.

## **(b) the experience of people with complex care and support needs in developing, enacting and renewing NDIS plans**

**-Emphasis on Diagnostics-** Those with complex care and support needs are being directly disadvantaged by the NDIA's shift to diagnostics to determine ongoing access and higher level support budgets. Participants with severe levels of intellectual disability are required to provide updated assessments every two years or their severity level is no longer recognised. The NDIA state that they do not fund diagnostic assessments when families request support for this. A cognitive assessment usually costs upwards of \$800. Very few families can afford to spend this amount every two years to prove how severely disabled their family member is, particularly when they are already overrepresented in low socio-economic statistics.

**-Lack of knowledge/training in complex needs by Planners-** Despite having a permanent and severe disability, a participant without up to date diagnostics is viewed as someone who could potentially be "high functioning" after a year or two of support, and their plan budgets reflect this assumption. Those with complex care and support needs will generally require high levels of support for the duration of their lifespan, and this support is often to maintain skills and/or mobility, and to prevent regression. "Lack of progress" is often cited as the reason for reducing or removing supports on the grounds that they are not "value for money".

**-The Planning Pathway-** Earlier in the scheme, those with complex needs had their planning done entirely by an NDIA Planner. While this didn't always result in ideal plans, there was far less opportunity for confusion and loss of information than in the current pathway where participants meet with an LAC (or ECEI for under 7's), who pass on the information to the planner who builds the plan and approves supports having never met or spoken to the participant. For those with complex care and support needs, information is not being passed on to Planners, who are often also not reading or giving due consideration to the additional reports and recommendations provided by the participant's supports, leading to inadequate plans. LAC's and ECEI's have reported that planners have refused to consider any reports or information apart from what is submitted to them from the LAC/ECEI.

Those who cannot write a quality participant statement to submit are also at a distinct disadvantage and there is little to no pre-planning support available for those wishing to access this. Many participants/families state that they verbally told their LAC/ECEI detailed information about their complex support needs but there is no guarantee that the LAC/ECEI will remember, let alone record and pass on this information given their workloads and number of cases they are handling.

**-Failure to follow legislation-** Planners are routinely failing to consider their own guidelines and legislation when determining supports for participants. This is particularly evident regarding funding for Core Supports for children and "Supports to Sustain Informal Supports". Part 3.4 of the National Disability Insurance Scheme (Supports for Participants) Rules 2013 (Revised 2016) states the following:

3.4 In deciding whether funding or provision of the support takes account of what it is

reasonable to expect families, carers, informal networks and the community to provide, the CEO is to consider the following matters:

(a) for a participant who is a child:

(i) that it is normal for parents to provide substantial care and support for children; and

(ii) whether, because of the child's disability, the child's care needs are substantially greater than those of other children of a similar age; and

(iii) the extent of any risks to the wellbeing of the participant's family members or carer or carers; and

(iv) whether the funding or provision of the support for a family would improve the child's capacity or future capacity, or would reduce any risk to the child's wellbeing;

Source: Australian Government, Federal Register of Legislation

In a majority of cases for children under the age of 12, planners are justifying removing or denying Core supports on the grounds that full support of a child is a reasonable expectation of all parents. They are then choosing to ignore sections (a)ii-iv that require them to consider how a child with severe disability's care needs may substantially surpass those of their typically developing peers, the risks to the child and family's wellbeing should support not be provided, and the benefit of that support for a child in increasing their capacity.

There is also a lack of understanding of the role that a Support Worker plays in supporting a child to increase their capacity and work towards achieving their goals. Support Work is often referred to as "babysitting" by planners, with families told that the NDIS does not fund this. The lack of understanding of what is required to develop capacity across all settings of a child's life is leading to a lack of supports outside of a clinical setting. Children are being placed in a position where they will have no support to access the community until they turn 13, where if that child and their family was given the support to practise this skill from a young age, they could be capable of safely accessing the community for everyday errands such as groceries or appointments, and able to focus on increased, meaningful social participation, or learning to travel train by the time they turned 13. The drive to reduce plan budgets now is only going to increase the support needs of complex individuals in the future.

**-PEDICAT-** The Pedicat tool used to assess functional ability is ill-suited to measuring the support needs of participants with severe levels of autism and intellectual disability. Those who have good mobility will score above their true ability using this tool, and it fails to take into account that for these participants, having full mobility can often increase their support needs and risk levels when they also have high levels of challenging behaviour. E.g. A 7-year-old with Level 3 Autism and a Severe Intellectual Disability may be large for his age and very strong. He is able to run very fast and climb fences or onto rooftops. This same child may have no sense of danger and is attracted to cars and water, so in the event that they wander or run from their parent or caregiver, they can potentially be placed in a life threatening situation very quickly.

**"Primary Diagnosis"**- Those with complex care and support needs often have several diagnoses that severely impact their functioning. The NDIA have claimed that it is at the discretion of the planner whether they take into account any additional/secondary diagnoses. This has seen individuals with a primary diagnosis of autism or intellectual

disability denied equipment for mobility (e.g. wheelchairs) as their primary disability on their NDIS record is not a physical one.

**-Lack of Community Options-** Planners incorrectly assume that people with complex needs can access community based supports or care from informal supports. For example, Core supports are being systematically removed from plans for children under 12 in a significant number of cases as the NDIA claim that 24-hour care is a reasonable expectation of families and that children can access child care if needed. This assumption fails to take into account the inability of mainstream child care services to cater to children with very high support needs requiring 1:1 support, particularly where those children have complex medical needs or high levels of challenging behaviour. This also fails to take into account the lack of available services for older disabled children who cannot care for themselves at home when their parents work, and for whom there are no options for mainstream OOSH or Vacation Care. The only supports that are available for children with high support needs is via NDIS providers of Core supports offering centre-based or community access social and leisure groups and individual supports.

**- “High Intensity” funding and 1:1 supports-** Providing support for someone with complex high support needs requires more experienced and more highly trained staff at more intensive ratios. There is very little consistency in across plan budgets in what complex individuals are allocated, and there is even more inconsistency in what planners consider to be a “high intensity” case, and which is not. Similarly, individuals requiring 1:1 supports are not being funded this for group scenarios where a 1:3 or 1:2 ratio would put the individual, staff and other service users at risk. This has led to a situation where services simply cannot afford to provide supports for those with complex needs and are opting not to take these cases on. This issue is only going to increase with the updated requirements for Behaviour Support implementation and restrictive practice requirements of services.

**-Lack of advocacy-** Participants with complex care and support needs are poorly represented and supported in planning meetings. Unless they have a family member or Carer who can adequately advocate their needs in writing there is little chance of their needs being properly understood or catered to in their plan, and the reality is that these are often the families who have the lowest capacity to advocate effectively for their family member. There is a clear lack of trained planning staff at all levels of the Pathway with a working knowledge of what is needed to support someone with complex care and support needs across all aspects of their life.

Their families are usually under higher than usual levels of carer stress, suffer from chronic sleep deprivation and poor health from a lack of time and funds to care for their own health due to the extremely high levels of care they are providing around the clock for their family member. Family breakdown is extremely common, as are chronic mental health conditions as a result of years of untreated carer stress and depression. These families are some of the most worn-down in our community and often do not have the capacity to advocate on the level that is required for their family member to access the supports that they need.

**-Low levels of Specialised Coordination of Supports-** Support Coordination for those with complex care and support needs is ongoing and requires high levels of specialised skills and

knowledge. This intensity and complexity of support is far beyond that of mid-level Support Coordination, yet that is the level that is usually funded (on the rare occasions that Support Coordination is even included in the plan). It costs providers considerably more to offer support to complex cases, yet this is not reflected in the mid-level Support Coordination rate (approx. \$96 v \$182 for Specialised Coordination of Supports). Once again, providers are choosing not to provide service to complex cases as the supports funded in their plan are not cost-effective. This leads to participants not accessing the highly trained and skilled clinicians they need for this level of support.

### **(c) the accessibility for Early Intervention supports for children**

Early Childhood Supports are not being provided in a timely or effective manner due to the following factors:

- Triaging of cases by Early Childhood Partners**- many children who meet the eligibility requirements are not accessing the scheme because ECEI's are not able to keep up with demand. Children with disabilities requiring interventions from birth (e.g. Down Syndrome, Cerebral Palsy) are going without due to long waiting periods for access to planning. ECEI partners are overwhelmed with trying to keep up with planning workloads and those who are waiting or who don't meet eligibility are missing out on services altogether.
- Programs previously funded under block funding arrangements are no longer available, yet replacement programs aren't being set up as they aren't cost-effective under the NDIS price guide (e.g. Play groups for very young children with early 0-2yrs diagnoses, support for navigating school application and transitions for special education, supports for assisting preschool and families more effectively).
- Most ECEI's are not aware of the transdisciplinary model Early Childhood Supports allows for, and as a result are not informing families that they can access a Keyworker to fill this role using their NDIS funding, or explaining what this type of service provides.

### **(d) the effectiveness and impact of privatising government-run disability services**

-**ADHC/FaCS Acquittal Delays**- We have had some self-managed service users identify that their child's short term accommodation, or centre based respite had been covered by ADHC under block funding arrangements when using their service for overnight stays in 2016/2017. This meant that when their plans were reviewed their budgets appeared to have had low usage which led to their next plan's Core budgets being significantly lower. The same thing is still happening this under the services which have taken over the private running of those formerly-ADHC services in 2017/2018. Families have contacted the service provider and the NDIA requesting invoices so that they can use their funding to pay for their support to no avail. They have submitted requests for internal review due to their low Core budgets, but because their current funding also looks untouched they are not prioritised and will likely face further reductions next plan. These are also services catering to some of the more complex participants in our region, who can least afford to have this funding reduced.

**(e) the provision of support services, including accommodation services, for people with disability regardless of whether they are eligible or ineligible to participate in the NDIS**

**-Lack of emergency options-** Participant families are being incorrectly told that they can access emergency respite services in times of crisis (e.g. hospitalisation of parents) via Commonwealth Carer Respite services, In-home Supports and via services such as Zest Care, which used to cater to exceptional cases where care was needed for children while parents were undergoing surgery or post-operative rehab. With the roll out of the NDIS these services have lost their funding and/or are no longer able to provide services to NDIS participants, even if their plan lacks Core Supports, as this is seen as the responsibility of the NDIS.

-Children and young people who do not meet the diagnostic eligibility for the NDIS are not accessing community based supports because they simply don't have capacity for the complexity of these cases where disability IS a significant factor. Mental health is a considerable area of need, particularly for teenage girls who present with autistic traits, but not enough to meet eligibility for the NDIS, but for whom their disability makes community based mental health services inappropriate and ineffective. They are essentially "not disabled enough" for NDIS and "too disabled" for mental health services. If the NDIA were considering functional impairments as per the legislation rather than relying on diagnostics many of these case would meet the criteria for eligibility.

**(f) the adequacy of current regulations and oversight mechanisms in relation to disability service providers**

While the rationale behind the Quality and Safeguarding (Q&S) Commission is a positive step in regulating NDIS providers and upholding the rights of participants there are some concerns regarding the time and costs of these regulatory processes for our consortium.

**-Certification Costs-** As a provider of Early Childhood Supports and Specialised Coordination of Supports, our service is required to undergo Certification. The cost of employing an independent auditor to assess the service, and the time required to prepare for this is excessive, and as a small organisation this cost is prohibitive. There has been no financial support provided for small organisations which lack the administrative resources to undergo these processes.

- **"High Risk" Categories-** There has been no justification of why Early Childhood Supports are considered to be "higher risk" than the same therapeutic services under their plan when the child turns seven. The child's therapy services do not dramatically change in practice on their 7<sup>th</sup> birthday, yet this support is considered lower risk and does not require certification. These "high risk" categories also require tertiary qualifications, membership of professional regulatory bodies and minimum levels of experience under the Guide to Suitability and Price Guide; all of which are already regulated by their respective



professional organisations to ensure that clinicians are meeting their obligations in order to maintain their registration (e.g. continued professional development, supervision, insurance, adherence to Code of Ethics, etc.).

**-Behaviour Support-** As an organisation we have relinquished Specialised Behaviour Supports as the requirements of providing Positive Behaviour Support, particularly where restrictive practice is involved is far too labour-intensive to justify the cost of providing this service. This is particularly the case when clients with more complex behavioural support needs, but who often do not have sufficient funding in their plans to account for the extra hours spent meeting the requirements under the new Q&S legislation.

**-Complaints/Accountability of the NDIA-** It is essential that the same standards that providers are held to also becomes the norm for the NDIA and its employees. There is currently very little transparency in NDIA decision-making, or accountability for poor performance or misconduct by NDIA staff (and their affiliates). The NDIA complaints team will often considering a verbal apology within a month to be all that is required to resolve a complaint. Complaints to the Ombudsman only result in an acknowledgement by the NDIA of the recommendations made by the Ombudsman with no tangible changes occurring to resolve their complaint.

NDIS Planners have a significant impact on the wellbeing of participants via the decisions they are making and are acting in positions of considerable power over some of the most vulnerable people in our community. Their workforce needs to be held to the very same standards that providers are required to maintain, and there needs to be a regulatory department within the Q&S Commission dealing specifically with complaints about NDIS staff and processes.

## **(g) workforce issues impacting on the delivery of disability services**

**-Demand Exceeds Supply-** There are simply not enough therapists to cater to the sheer number of children seeking supports in the Nepean/Blue Mountains region. Wait lists are extensive in all services, and therapists are bound by their respective professional standards to limit their caseloads to safe levels to prevent burnout and to maintain quality. Many children are going without services while they are waiting for supports to become available. This can also lead to a situation where a child begins supports late in their plan, then has their budgets cut due to low usage on review, leading to them having to reduce the services they had waited so long for.

**-Cancellations-** recent changes to the cancellation policy have been helpful, but inconsistency in attendance remains a problem with many clients, particularly families with children who have complex health conditions or who have multiple children with disability. During periods of high levels of illness (e.g. winter) business viability is a challenge as time slots cannot always be filled on short notice but therapists may have multiple late cancellations.

**-Uncertainty of Funding-** Tiered pricing levels were recommended in the McKinsey report based on complexity of cases and is still being considered. This poses a serious threat to the

viability of our organisation and does not take into account the complexity of therapeutic services being delivered to NDIS Participants. As it stands at present, we would be unable to offer service to lower tier clients at the proposed rates, which are \$70 less per hour than the current price guide allows, and maintain a sustainable service.

**-Ongoing Administrative/Portal Issues-** While some good improvements have been made to the portal such as providers being able to edit and terminate service bookings there remains ongoing difficulties with claims being accepted and paid on time. There are also regularly considerable gaps between plans for participants during which time we are expected to continue to provide service while not being paid until a new plan is approved weeks to months later.

**-Budgeting Difficulties-** Many participants assume that “agency managed” means that they do not need to monitor usage of their plan. Many also assume that providers can and will do this for them. This leads to frequent situations where participants/families overcommit their funding and cannot afford to pay for services as they have already made service bookings elsewhere. Considerable administrative time is spent on chasing these funds and supporting families to understand how to navigate the portal and to manage their budgets.

**-WHS Concerns-** Staff burnout is a serious concern with the increased demands of being an NDIS provider. Staff are spending excessive amounts of personal time preparing reports, dealing with administrative challenges with the portal, and advocating on behalf of their clients to NDIA staff/LAC’s/ECEI’s. They are often the ones who are supporting families who are distressed by their plan budgets being reduced, and they are the ones supporting highly-anxious families as they prepare for their child’s NDIS review- often on an unpaid basis. The lack of formal family/carer support services has shifted the demand for this support to therapists, as they are often the only trusted support in the child’s life. This support is generally unpaid, but the toll taken on therapists is considerable.

## **(h) challenges facing disability service providers and their sustainability**

As stated previously, the costs of meeting certification obligations poses a challenge to the sustainability of our business.

At present we also have little confidence when submitting a claim to the NDIA whether it will be accepted and paid on time, and the increased administrative workload and associated costs to our business since becoming a provider have been considerable (this is despite already being a provider of HCWA/FAHCSIA, BetterStart and Medicare services prior to NDIS).

Uncertainty regarding the potential introduction of funding tiers remains a threat to sustainability. There is great concern that children accessing our services will be allocated lower tiers based on their perceived severity by a Planner without clinical training to accurately assess this, or that some children, particularly those with Level 1 or 2 Autism may not have their support needs properly understood, and will be allocated a lower funding tier

despite having needs that are of high complexity to treat. Recommendations made by therapists are frequently ignored when supports are allocated, or are perceived as “self serving” (i.e. trying to increase business for the therapist), so there are very real concerns that this would also be the case if/when funding tiers are allocated.

### **(i) incidents where inadequate disability supports result in greater strain on other community services (e.g. justice, health)**

**-Education-** Many of our more complex clients, particularly those from culturally and linguistically diverse backgrounds, or where their parents have a disability or mental health difficulties, are relying on schools to support them to access the scheme, to understand their plans and to assist them with locating services. These participants should be approved for Support Coordination in their plan but rarely are.

**-Health-** There is a concerning pattern of planners refusing to even discuss relevant health conditions, or supports/equipment made necessary to manage health conditions due to a participant’s disability and stating that they are the responsibility of Health. Some examples are:

- Core supports being denied when higher supervision levels being required due to intractable epilepsy
- BSL monitor for a non-verbal child with Type 1 Diabetes and Severe Intellectual Disability so their parent could monitor their levels at all times, and a child with
- incontinence supports being denied as incontinence was caused by rectal prolapse despite this occurring as a direct result of their having low muscle tone caused by Down Syndrome

### **(j) policies, regulations or oversight mechanisms that could improve the provision and accessibility of disability services across NSW; and**

Suggestions include:

**-A Quality and Safeguarding Commission team to manage complaints and compliance issues about the NDIA.** This needs to happen as a matter of priority. The Agency is currently completely unaccountable for meeting compliance outcomes enshrined in legislation and their own policies and Operational Guidelines. These compliance breaches have been the subject of ongoing reports from the Commonwealth Ombudsman and Administrative Appeals Tribunal and ongoing appeals to the Minister by local MP’s regarding systemic issues with planning and implementation of plans.

-All complex cases (e.g. severe-profound level of disability, children in care, complex family situations) to be planned and reviewed with a Senior Planner, not with an LAC or ECEI, who has professional experience in working in complex care and support needs, with tertiary qualifications to be the minimum standard for recruitment.

-The participant to be able to see a draft of the plan and be given the opportunity to provide feedback and corrections before the plan is approved to reduce the amount of internal reviews.

-Participants should be able to choose to have their Department of Education records made available to the NDIA. This would often reduce the need for families to self-fund updated diagnostics to prove severity levels as School Counsellors will often reassess cognitive and adaptive functioning to meet DEC requirements for children in special education. This is particularly true of children with severe levels of disability.

-An expedited process to apply for, and have equipment approved for those with physical disability so their health and wellbeing does not decline while they wait for unscheduled reviews.

-Ability to transfer funding across support budgets providing the service accessed addresses the participant's goals.

-Support Coordination to be allocated as a stated support to assist with implementation of the plan, and responsibility for this to be removed from LAC's who cannot sustain their current workload.

-Complaints management to be reviewed and improved with accountability measures introduced to ensure tangible improvements to NDIA Quality outcomes.

-Review of the inclusion of "Supports to Sustain Informal Supports" and training for NDIA staff in when this is to be applied.

-Reinstate funding and support for emergency care services such as Commonwealth Carer Respite, and make this funding available to NDIS Participants who may not have adequate funding in their plan for Core Supports

Thank you for the opportunity to contribute a submission to this Inquiry. If I can provide any further information or clarification of the issues raised in this submission, please do not hesitate to contact me on .

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