

Submission
No 352

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

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Uniting

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Uniting Practice and Quality

Uniting Disability

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Parliamentary inquiry

**Implementation of the National Disability Insurance Scheme
and the provision of disability services in New South Wales**



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About Uniting

Uniting is the service and advocacy arm of the NSW and ACT Synod of the Uniting Church in Australia. We work to *inspire people, enliven communities and confront injustice*. We are one of the largest not-for-profit community service providers in NSW and the ACT and provide aged care, early learning, services for vulnerable children, young people and families, and people with disability.

Uniting is a registered provider of National Disability Insurance Scheme (NDIS) supports, providing support to approximately 500 NDIS participants with a workforce of approximately 150 staff. Uniting holds a unique position as not only a registered provider, but also as an National Disability Insurance Agency (NDIA) funded Local Area Coordinator in NSW. In addition, we provide services in a range of other sectors that are impacted by or have interface with the NDIS, including out-of-home care, youth and homelessness, and services for people who are ageing.

We appreciate the opportunity to provide evidence at this Inquiry. Uniting has always supported the NDIS, and we continue to do so. We welcome its aims of giving people with disability more choice and control, of providing them with the resources necessary to live a dignified, active, meaningful life, and of ensuring Australia is a more inclusive society. We welcome the change in philosophy which sees support as both a right for, and an investment in, people with disability.

Uniting acknowledges that a great many people have benefitted from the roll out of the NDIS, and are currently experiencing enormous improvements in the way their supports are funded and provided. The NDIS has also acted as an effective driver for individuals and communities to think about how informal supports may be used differently for people with a disability who wish to live a life more purposefully outside of the disability service sector.

However, we also acknowledge that for many other people, the NDIS has not lived up to expectation. In some cases, we are aware that it has produced outcomes that are worse than experienced prior to their transition to the NDIS.

We have outlined our key issues below, following the items of the Terms of Reference for this Inquiry.

a) The implementation and success or otherwise in providing choice and control

In our experience, many participants and their families have benefited from the greater choice and control provided by the NDIS. This includes, for example, the positive experience of greater flexibility in the support they purchase, enabling them to decide the hours/days, what they buy and from whom. We note that for those who receive funding for assistive technology for the first time, the experience can be life changing.

Ian has been with Uniting for a number of years. Ian has severe mobility issues. He never had any assistive technology prior to the NDIS. His typical day started with getting up in the morning, having his personal care attended to and being transferred to a lounge chair where he would sit for the whole day and either watch movies or play video games. Attending medical appointments was extremely challenging and Ian had no community access. After many assessments, reports and advocating with NDIA, Ian was funded and received his very first wheelchair and an appropriate recliner chair in August 2018.

Ian feels like he now has so much choice and the freedom to do what he likes during the day. His family often jokes that Ian has no excuse but to be out and about in the community. With the support worker, Ian was able to enjoy a cup of coffee in a café for the very first time. Ian is now planning on reviewing and rating each café he visits.

Variation between participants

It is inherent in a Scheme that prioritises an individual and tailored planning process, that there will be variation in the plans that are given to people. However, in our experience:

- There is often a much greater degree of variation than one would expect, given the degree of difference between participants' need and functional capacity.

Ali and May are sisters with similar support needs. Both girls have inconsistent sleep. Both girls have similar goals regarding social skills, therapeutic support and formal supports in implementing routines. May received \$9,782.24 in Support Coordination, Ali received \$1,881.20. May received over \$10,000 for behaviour intervention supports, Ali received nothing in this category. May received \$37,143.56 in core supports, Ali received \$5,333.86.

Mohammad is a wheelchair user with no ability to self-transfer. He lives with his family and requires support for all aspects of daily living. Mohammad received core support funding of approximately \$59,000. Tran is a wheelchair user with no ability to self-transfer. He lives with his family and requires support for all aspects of daily living. Tran received core support funding of approximately \$17,000.

- Inconsistent plans are commonly seen for people with complex needs, for people from culturally and linguistically diverse backgrounds and for Aboriginal people.
- Inadequate plans seem to be commonly aligned to lack of capacity within the individual (and/or their circle of supports) to strongly advocate for themselves, articulate their own needs or to understand and navigate the NDIS, including the administrative and technology based aspects such as the portal and myGov.

Uniting works with an Aboriginal family who has multiple school aged children all with disabilities. During the planning meetings the family requested flexibility and for the NDIA planner to recognise their cultural values while allocating support budgets. The family had made it very clear that they do not wish for someone to come and look after their children but that they would like to allocate some funds for domestic support and yard maintenance which would allow the family to look after the four children. This was interpreted as the family does not require Core Support Funding. Another family requested for a Plan Management service to have the flexibility of choosing Non NDIS Registered Aboriginal specific providers. They were given plan management funding and then had it taken away without any explanation.

- Those living in regional areas are disadvantaged by thin markets offering limited choice.

Our experience is consistent with the NILS Flinders University Evaluation of the NDIS, which identified that the Scheme works best for those who are able to strongly advocate and who live in urban areas.

Systemic issues

Uniting note that the September 18 Commonwealth Joint Standing Committee on the NDIS recommended that the NDIA ensure support coordination is adequately funded in plans to meet participant needs and not limited to a fixed period. Uniting would support the proposition that inadequate and sometimes non-existent levels of support coordination is proving problematic for people, particularly those with complex and intersecting needs.

Whilst people in these situations do sometimes receive Support Coordination within their plans, in Uniting's experience, the rest of the plan is often inadequate, which means that precious Support Coordination hours are spent in applying for and supporting reviews of the plan. We are seeing that for many participants, Support Coordination hours are being reduced in subsequent plans without any methodology being provided by the NDIA.

Maria's support coordination allocation of 74 hours was exhausted 8 months into her first Plan. She has only received 45 hours of support coordination in her new Plan. There is no evidence to support Maria's capacity having increased. Maria's life remains complex due to her husband and primary carer's health being poor. Her husband requires dialysis treatment in hospital 3 days/week. He experiences regular low energy levels, poor memory and confusion. This family requires a significant level of support with managing their Plan.

Tony is a participant with complex needs, he requires a minimum of six hours support per day, including overnight support. Tony has limited mobility. Tony received 104 hours of support coordination in his first plan. At first review this changed to 44 hours, at second review 25 hours and at third review, 44 hours. Tony's support needs did not change throughout this time, and his capacity to manage did not increase.

Some participants are fearful about upcoming plan reviews because they know the intent is to reduce their hours of Support Coordination. The methods of the NDIA's actuaries which are used to achieve these reductions, must demonstrate more transparency and be open to scrutiny.

The rationale for reductions should be clear and provided to participants and be supported by evidence on required reasonable and necessary support. Inconsistent experiences of participants are not assisted by a lack of consistency in the application of reasonable and necessary guidelines across the NDIA and by inconsistent pre-planning and plan review work undertaken by LACs.

The lack of Specialist Disability Accommodation (SDA) in NDIS plans and an undersupply of SDA housing means that choice and control regarding where people live is very limited. Accommodation and housing planning processes are still very immature and they are not producing best (or consistent) outcomes for people with SDA in their plans. Uniting are hopeful that this will improve in the near future. There is a lack of data regarding SDA to enable developers to feel confident in this market also hindering market development.

Degenerative conditions

For some cohorts traditionally locked out of funding, for example, people with neurological conditions such as Multiple Sclerosis and Motor Neurone Disease, the NDIS has brought life changing support. However, we note that many of these conditions are degenerative, and we have observed the NDIS struggle to adapt and flexibly meet

people's changing needs. People supported by Uniting who require a change of circumstance plan review are experiencing significant wait times as the NDIS works through the 'queue'.

b) The experience of people with complex care and support needs in developing, enacting and reviewing NDIS plans

In the absence of tailored participant pathways supporting a more person centred planning process, in addition to the issues discussed above, we have experienced a very high rate of review and appeal among Uniting participants. This is on the grounds that plan funds are not adequate to meet the reasonable and necessary needs of the participant. Our staff are often supporting reviews despite the Support Coordination funds having been expended, leaving the organisation to work on a pro bono basis regularly.

Uniting works with many participants who have needs which require access to the mainstream service sectors. These are predominantly health, mental health, justice, child protection and education. The individualised nature of the NDIS, and the shift away from a holistic case management approach, means that these services are all provided in isolation, if they are provided at all.

Advocacy services are limited and, according to the NDIS, it is not the role of support coordination to advocate nor to provide the kind of case management approach that would enable these intersecting services to work holistically and in a coordinated way. Whilst supporting a participant at an Administrative Appeals Tribunal hearing recently, a Uniting Support Coordinator was told by an NDIA Special Advisor that she could not bill for her time at the Tribunal as Support Coordinators are not advocates and it is not their role. The participant had requested the Support Coordinator's assistance at the Tribunal hearing in lieu of a complete absence of familial support.

There is a lack of funding in Plans for case conferences and other related meetings which would enable holistic work with a range of agencies. Communication channels are complex or non-existent, with staff trying to do their best in an environment without finalised agreements between those NSW based services and the Commonwealth.

One of Uniting's Support Coordinators recently worked with Jane, a 59 year old participant with an acquired brain injury. She lives with her 76 year old mother who is her carer. Jane's support coordination hours had been expended and the Support Coordinator was waiting on a Plan review.

Jane's mother was unexpectedly hospitalised late on a Friday afternoon. Jane requires full care with all activities of daily living and displays very challenging behaviour with people she doesn't know. She couldn't be left alone, so attended the hospital with her mother. The hospital sent Jane to her sister's house. Her sister has a child with autism.

On Monday the sister told the social worker at the hospital that she was unable to cope with Jane's extreme behaviours, that she felt unsafe herself and fearful of having Jane around her children. Jane was not allowing her sister to help her with her personal care, and was covered in faeces. Jane's sister was intending to call an ambulance to have her removed from the house. The hospital social worker contacted the Uniting Support Coordinator.

The Uniting Support Coordinator contacted agencies that had previously supported Jane. None were willing to work with her. The Support Coordinator contacted Jane's Local Area Coordinator. By Monday evening, the LAC had located short term accommodation for Jane. On Tuesday the LAC called the Support Coordinator to

advise that a six month plan had been approved giving more Support Coordination hours, and that the Support Coordinator was now to take responsibility for Jane.

c) The accessibility of early intervention supports for children

We do not have a comment on early intervention supports for children as that term is traditionally used.

We are, however, extremely concerned about gaps in support for children with disabilities and their families. We have witnessed a sharp increase in children with disability being 'relinquished' (surrendered) into voluntary out-of-home care in the past two years. A significant contributor to this is the closure of preventative services, which were previously funded by the NSW government and targeted to families of children with high support needs, challenging behaviours, and at high risk of relinquishing their children into state care. These programs have closed because the funding was transferred to the Commonwealth under the NDIS, but the NDIS does not provide equivalent supports to families (such as support for parents and other carers). The individualised funding model of the NDIS does not allow for a holistic and coordinated response to families experiencing complex issues.

Mainstream family preservation and restoration programs are not an adequate substitute in their current form. These programs have strict entry criteria, requiring referrals from FACS based on verified child protection concerns relating to abuse or neglect. However, child protection concerns are not usually present for these families, and the issues that these programs attempt to address are very different.

Tom is a 14 year old boy with autism and intellectual disability. Tom is 180cm tall and weighs approximately 100kg. Tom is predominantly non-verbal, incontinent and displays very challenging behaviours, particularly against his mother and siblings. Tom's parents have recently separated and Tom has been living with his father due to the risk of violence to his mother and the other children in the house. Tom has been repeatedly excluded from school and has been unable to access after school hours' care. Tom's father is the primary income earner for the family and has recently had to take extended time off work to care for Tom.

Prior to the NDIS, Tom had a case manager within ADHC who would support Tom's parents in organising therapy and allied health appointments, in home supports, centre based respite, liaise with the school, organise behaviour reviews and support plans with Tom's psychologist and provide emotional support to Tom's family, including linking his siblings to support groups. The case manager would hold regular case conferences with all the professionals involved in Tom's support and development.

Since the NDIS, Tom has received some funding for each of these components of support, except for case management, which is not provided under the NDIS. His Family receive no supports under the plan. The roll of bringing all these different components of Tom's support together, has fallen to his parents with some assistance from the Support Coordinator. Tom has limited funding to use for centre-based respite (or short term accommodation), receives no funding for ongoing liaison or advocacy with the school.

His parents and the Support Coordinator are struggling to find staff who are willing to work with him at home due to his challenging behaviours. After several months of caring for Tom with very little support (despite having an NDIS plan), Tom's father made the difficult decision to relinquish the day to day care of Tom, and, having accessed Uniting's respite service, announced that he would not be taking him home again.

The current outcome for children like Tom, is that, despite there being no child protection concerns about Tom or allegations of mistreatment or abuse within his family, this situation requires a report to FACS and places Tom into the state based child protection system. The NDIA insist that they will not pay for his accommodation needs. The FACS funding system requires that this come through as a child protection issue. As Tom is an unlikely candidate for a foster care placement, Tom must be placed under a temporary care order through the Court, with a Special Care Arrangement put in place between FACS and Uniting, in order that FACS can fund the cost of his residential placement in a facility that is only designed for short term stays. This is despite the fact that the entire situation is a response to Tom's disability and very high support needs, that his parents were still willing to retain legal responsibility for Tom and are still committed to advocating for and supporting him.

Uniting are aware that NSW FACS are trying to fill the void with ad hoc "Special Care" arrangements in an effort to keep children out of statutory OOHC and we applaud these efforts but remain concerned that a systemic, longer term solution is not apparent.

d) The effectiveness and impact of privatising government run disability services

The privatisation of State-based disability services has had significant consequences for aspects of service provision that do not easily fit within an individualised funding model. Within Uniting, we see this effect most profoundly within specialised behaviour support services. We work with participants who require Behaviour Support Plans in order for us to do so safely and effectively. However, we have no control over whether behaviour support is adequately funded within their plans, and no point of referral for specialised supports to be put in place. Prior to privatisation, NSW had a highly effective and specialised behaviour support service that would provide support, training and education to staff working with people with complex behaviour, in addition to the development of individual support plans. Uniting does not provide behaviour support services, yet we do implement them and we absorb the risk of supporting people who do not have access to this service type.

Additionally, the existing and new requirements regarding behaviour support are costly to implement, and are non-billable for registered providers (non-registered providers do not have the same requirements).

There are many people in NSW who will not be eligible for an individually funded plan under the NDIS, and who could potentially previously have accessed state-based block funded services. These people would typically be accessing services such as information and advice, support for psychosocial needs, and supports for family members. The NDIS Information Linkages and Capacity (ILC) Framework through the 5 stream approach (Information, Linkages & Referrals, Capacity Building for mainstream services, community awareness and capacity building, individual capacity building and LAC) was intended to fill some of this gap. Investment in ILC functions such as community education, broad based interventions and capacity building strengthens informal support and promotes the social and economic inclusion of people with a disability. Over time this can reduce the demand for, and level of support required through individually funded supports (and thereby reduces long term Scheme costs).

As yet we are not seeing NSW ILC funding announced in 2018, address the 5 streams in any systemic way. Uniting would observe that the projects that are funded do not provide state wide or cohort wide coverage, so there is still a risk of services via postcode or according to very specific needs or diagnosis.

NSW has had the benefit of the state wide Ability Links service, with a target cohort of the (much broader) disability population in NSW. However, within our Ability Links service, we find our staff taking on case management functions, in order to fill the gap that has been left in this area. This is often particularly to deal with emergency situations until state funded services can be engaged (particularly prevalent in Aboriginal communities and in areas where the NDIS market is thin). We are also finding our staff taking on Support Coordination roles for people who have NDIS Plans, but who have expended their Support Coordination budget. Ability Linkers also often find themselves providing family centred support post NDIS transition as families and carers find themselves locked out of support they previously had access to.

Uniting strongly supports the ILC Framework be properly and full funded by the NDIA and that the functions currently performed by NSW Ability Links must be incorporated into that model to ensure people who are eligible and ineligible for the NDIS have full access to an ILC Framework targeted towards building a more inclusive and supportive community for people with a disability, their families and carers.

e) The provision of support services, including accommodation services, for people with disability

Supported Independent Living requires a quoting process, which Uniting has found onerous and resource intensive. This process is non-recoverable for service providers. We estimate our relatively small number (26) SIL quotes cost in excess of \$42 000 to prepare.

Specialist Disability Accommodation currently has an unclear process of assessment and approval, and there is a significant variation between NDIS regions as to the level of understanding of SDA by Planners and LACs. A lack of data from the NDIA means developers are seeing this as high risk. As a result, we are experiencing an undersupply of housing, with no coordinated approach to information sharing between potential providers of SDA and the market for SDA tenants. There is a lack of accommodation planning funding within plans, meaning participants cannot access the specialists they need to plan for accommodation option that might better suit their needs.

Uniting already provide a wide range of accommodation and housing options to a wide range of customer groups in NSW and has access to the means to invest in SDA in NSW. However, despite working for over 12 months to progress this work, uncertainty and a lack of clarity is prevalent and impacting organisational commitment to the risk involved in this market.

f) Adequacy of current regulations and oversight mechanisms in relation to providers

The full impact of the regulations and oversight mechanisms under the NDIS Quality & Safety Commission are yet to be felt in NSW. We do, however, believe there is a significant inequity between requirements imposed on non-registered providers and registered providers. Providers who are not registered have no certification or ongoing auditing requirements, do not have to report on incidents, and do not have many of the behaviour support requirements regarding process and reporting. Uniting estimates that meeting all of the requirements of the Commission annually requires at least one full-time role. This is, at present, is a non-billable and non-recoverable expense.

The inequitable and onerous nature of this two-tiered system may have the undesired consequence of encouraging registered providers to either withdraw from the system entirely, or to concentrate on self-managed and plan-managed activities. If this occurs on

a sufficiently large scale, it may lead to the development of a broadly unregulated disability sector, and may drive poor practice underground.

g) Workforce issues impacting the delivery of disability services

It is becoming difficult to recruit and retain suitably qualified staff. Our experience indicates multiple factors may be contributing to this:

- Casualisation and fragmented working times, characterised by multiple short shifts, low pay and uncertainty of tenure all contributing to a lack of incentive to choose a career in the disability sector;
- lack of funding for professional development and ongoing learning particularly for those providers supporting people with complex needs, where workforce upskilling is vital in addressing participant needs and keeping everyone safe;
- the NDIS price guide creating unrealistic assumptions around the amount of time staff need to spend undertaking non-client-facing functions, which appears to be contributing to low morale and sector exodus;
- un-registered providers hiring people without compliance checks, posing risks to participants who purchase supports through them;
- insufficient opportunities for career progression; and
- the absence of a national plan to guide workforce strategy, which is a particularly serious issue given the deregulation of several related sectors including HACC, Disability, and potentially Residential Aged Care.

We are concerned that these factors, when combined with competition between providers for staff and insufficient coordination and planning, will lead to significant workforce shortages in several sectors.

h) Challenges facing disability service providers and their sustainability

Financial sustainability for core supports

At Uniting, provision of service under the Core Supports category make up 80% of the projected support volume for the 18/19 financial year. With all costs included it is predicted that Uniting's margin on delivering core supports will be approximately -20% for this financial year. This is non-recoverable under the NDIS.

There have been service providers (small and large) leaving the Core Supports marketplace. Uniting are currently considering our long term position in the market.

Service Delivery for people with complex needs

Uniting pay staff SCHADS 4 compared to other service providers (as per McKinsey review) who pay between SCHADS level 2.2 to 2.4. Uniting aims to provide a professional and high quality service, and therefore we are trying to attract and retain highly skilled staff with experience to work with people with complex needs and/or challenging behaviours through Support Coordination.

The costs of supporting people with complex needs are not well reflected in the price guide, as they usually require additional services and business supports, including costs associated with Incident Management and Reporting obligations.

Additionally, staff often require extra training, supervision and support when working with people with complex needs. The price guide does not allow for staff to receive sufficient

induction, workplace training, to participate in team meetings, debriefings and receive supervision.

Cost of transitioning to NDIS and cost of interacting with NDIA

Uniting cannot overstate the level of capacity, expertise, case reserves and infrastructure that has been required in transitioning to the NDIS. These costs are unrecoverable. We are now experiencing significant costs associated with the reporting and certification requirements of the NDIS quality and Safeguards Commission.

There are also significant costs incurred when interacting with the NDIA;

- NDIS portal problems
- Wait times to liaise with the NDIA on participant issues
- Cost of inconsistent application of the Scheme guidelines and time taken to rectify or seek clarification for participants
- Cost of Supported Independent Living quoting

i) Incidents where inadequate disability supports result in greater strain on other services such as justice, and health services.

Our discussion of early intervention services for children, above, identifies strain on the child protection system from changes in the nature of support available to at-risk families. We are also aware of other strains, in particular within the health system. Within our support coordination service, we have worked with several participants who have remained in hospital months beyond when they could have been discharged. This reliance on the health system was entirely due to the lack of suitable accommodation within the community. This includes SDA, but also inadequate funding or very long waiting lists for home modifications.

j) Policies, regulation or oversight mechanisms

Please see our discussion of regulations and oversight mechanisms above.

k) Any other related matter

No comment