

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

Organisation: Community Industry Group

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Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in NSW

The Community Industry Group (previously Illawarra Forum) is pleased to provide a submission to the Legislative Council – Portfolio Committee No.2 Health and Community Services with regard to the ‘Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in NSW’.

This submission advises on key issues identified through the implementation of the National Disability Insurance Scheme (NDIS) across the wider Illawarra, Shoalhaven, Southern Highlands and NSW South Coast regions. The particular focus is on identifying limitations and opportunities, and how key implementation issues impact on disability service provision, NDIS participation and wider areas of community services, particularly relating to transport and health.

It is important to note that the Community Industry Group strongly support the premise of the NDIS and further acknowledge and support the vital role of the not for profit sector in the delivery of disability services across our region.

About the Community Industry Group

The Community Industry Group (CI Group) is the peak body working for community services organisations and for communities in South East NSW. We support community organisations, promote expertise and innovation in community development, foster industry development and advocate for social justice.

For twenty-five years, the CI Group has taken a leadership role in the local community services sector. We regularly engage with those organisations, services and individuals that work in supporting disadvantaged community members to collect their opinion, expertise and

recommendations. We held a discussion group with approximately 20 local disability support providers to inform this submission.

Background

In considering the overall success of the implementation of the NDIS in our region and its success in providing choice and control for people with a disability, we must first acknowledge the previous funding system that was available to people/persons with a disability (PWD), and the fact that it too was less than perfect.

CI Group support individual-based, person-centered funding models such as the NDIS, in comparison to the previous 'block funded' approach, to provide PWD with the necessary and reasonable funding that is required to live with dignity, to wholly participate in their life and the wider community and to do so with choice and control, as is the daily experience of people without a disability.

Our support for the continuation of the NDIS is unwavering, and throughout many discussions and consultations with both PWD and disability service providers (DSPs) we have identified examples of individuals who have experienced improvements in their lives, in terms of having increased choice in their daily activities, therapeutic support, accommodation and participation in the wider community.

In contrast, we know too well of the many people in our region who have not gained the funding in their NDIS plans to enable reasonable and necessary resources to participate in non-therapeutic supports, to purchase equipment, to access transport, or to gain access to community activities, employment, accommodation and other important necessities of daily life. We hear often the impacts, not only for the PWD but also their family, service providers and wider community sector providers, particularly the health care system.

For many NDIS participants and disability service providers, the barriers that prevent the successful implementation of the NDIS relate to quality, consistency and flexibility. Quality and consistency in plan content (with reference to Local Area Coordinator (LAC) and NDIA Planner advice, plan decision making and plan funding allocation) and flexibility in terms of acknowledging that PWD, particularly those with complex care and support needs may regularly require additional funding for each NDIS plan to provide for emergency/crisis type situations (for example, increased care requirements during periods of illness injury).

In addition, we have identified that many carers supporting people with a disability have limited capacity to self-manage an NDIS plan, or in some cases even ensure that the NDIS participant is actively engaged in an NDIA managed plan. Carers need more frequent and

higher levels of support in understanding, advocating for, engaging in and assisting in developing and implementing NDIS participant plans. Currently disability service providers are spending unfunded and unremunerated time and resources to provide education and support to carers, and to assist carers and PWD to seek plan reviews and upgrades. This is not financially viable for DSPs long-term.

The current challenges that the implementation of the NDIS presents, particularly in NSW, could be alleviated by further discussions and consultation with the NDIA, and through investigating opportunities that the NSW State Government can participate in. For example, the state government could take the lead in policy development, in building carer education, capacity and support resources, and in reducing barriers and restrictions between compatible NDIS funded supports and state government initiatives, such as enabling NDIS participants to readily access community transport in order to attend NDIS funded activities.

Discussion

The CI Group provides the following response to the Inquiry Terms of Reference points:

Implementation of the NDIS: success, barriers and opportunities in providing choice and control for people with a disability

Based on consultations with DSPs and the wider community across our region, we believe that the introduction of the NDIS as a process and funding model has in some cases increased the potential for PWD to gain choice and control in their daily lives. However, there is clear inequity in the experiences of PWD, and implementation of NDIS has not transpired into a common reality where all PWD, or even the majority of PWD, are experiencing increased choice and control in their daily lives.

The implementation of the NDIS has demonstrated some success (albeit inconsistent) in providing choice and control for some PWD. In the Illawarra region, this can be exemplified by highlighting the scenario of well supported youth or young people with a disability who now have *access* to an individual, person centered funding approach in the form of the NDIS, and have the *potential* to plan for and take control of their future, in terms of employment, training, accommodation, and participation in the community. It is crucial to identify that the NDIS provides a model of funding and structure for PWD to gain the support and skills needed to live full and engaged lives. However, in determining the success of NDIS implementation, we must not underestimate the importance of NDIS implementation as both a process *and* a way in which a PWD actively work towards/achieve life goals and increase inclusion within society.

Importantly, if NDIS implementation is flawed either as a process (on behalf of agencies such as the NDIA) or the implementation of an individual's plan is flawed due to lack of understanding of how to implement a plan or due to lack of access to services, the success of the NDIS as both a model and process in providing PWD with choice and control is compromised and the attainment of PWD's goals and ability to participate in life and the wider community is diminished.

The risk of failure in implementing an NDIS plan and delivering choice and control, is further heightened by the level of capacity of the PWD and/or their carer, together with level of education attainment, socio-economic status and so on. The NDIA has clearly identified Aboriginal and CALD participants as having low NDIS participation rates, and that those participants from these cultural backgrounds who have NDIS plans are not able to easily access the appropriate services or supports that they are funded for. Aboriginal and CALD participants often experience a lack of sufficient plan coordination funding and support, and in this region there has been no obvious dedicated regional strategy or approach by the LAC provider, or the NDIA, to reach or support these vulnerable groups. In this light, it is difficult to celebrate the easy-reach successes of NDIS implementation when those PWD who are most vulnerable, are statistically not better supported to participate in choice and control. Universal Access must be fundamental to the NDIS, if we are to meet the needs of our most vulnerable community members with a disability.

A local provider of services to CALD communities reported that:

- CALD communities appear to be significantly under-represented in receiving disability services generally in our region;
- Significant numbers of CALD consumers and carers report they are not able to understand the system or how to access services;
- Cultural and language issues impact on CALD communities' help-seeking behaviours to access a range of supports, which could be ameliorated by funding local, trusted organisations to educate and support them through the process.

Locally, a small number of language-specific information sessions have been convened by the CALD community sector over the past year and are generally well attended, indicating that there is a desire by the community for more information delivered by trusted community organisations.

Case Study

About 60% of clients of one provider in the Illawarra were recorded by the NSW Department Family and Community Services – Aged, Disability and Home Care - as “unable to be contacted” as part of the transition from CCSP services to NDIS. This is despite the service provider giving correct and up to date, verified contact details.

In addition, the success of the implementation of the NDIS is dependent on a number of market factors being stable and secure, such as the supply of a steady and sustained workforce to service NDIS participants and their various needs and service requirements, together with the need for disability support staff to be experienced and to be sufficiently trained.

The establishment and sustainability of a skilled and trained workforce within the disability services sector impacts the implementation of the NDIS across our region, affecting both demand and supply complexities, and impacting DSPs who now find themselves operating in an insecure funding environment (in terms of variations in year to year individual funding) which builds further constraints around workforce planning and spending. Many of our regional disability service providers are providing necessary but unremunerated support coordination to clients who are not funded for support coordination, which is clearly unsustainable and which further stretches an under-resourced workforce.

The role of LACs in the development of plan coordination and implementation is clearly identified by the NDIA, however as a region we are yet to observe this in daily practice, with LACs often citing high staff turnover and high workloads as a barrier in delivering initial plan coordination to NDIS participants.

This being said, it is possible for NDIS implementation to achieve greater levels of success and deliver greater choice and control to PWD. To do so, we call on State Government to advocate for all PWD across our region and across NSW, particularly those that are most vulnerable, and openly communicate with - and when necessary apply pressure to - the NDIA and LACs to ensure that increased support coordination is genuinely provided with all plans issued, and that both PWD and carers are further supported in increasing their capacity and understanding of plan implementation.

Experiences of people with complex care and support needs in developing, enacting and reviewing NDIS plans

For NDIS participants in this cohort, the overlap between disability support, clinical support and nursing care is often intrinsically linked, and cannot be separated, particularly in relation to the undertaking and funding of daily self-care tasks, or at times medical emergencies or mental health related crisis.

The inflexible nature of an individual's NDIS plan to be capped for a 12-month period, and not have a 'crisis' funding component that can be utilised in such situations not only places PWD in a vulnerable and high-risk care position, but also increases strain on the public health and hospital systems. In some cases, disability service providers are required to keep a PWD

hospitalised until sufficient clinical support and nursing care can be guaranteed upon discharge, with either the disability service provider absorbing the cost, or the PWD receiving less supports later in the 12-month NDIS plan period due to funding being expended at a faster rate to cover the increased clinical and nursing care needs. Reports of NDIA review processes to recoup such funds indicate reviews have not occurred in a timely or conducive manner for the PWD and the disability service provider. This scenario creates an increased level of risk and uncertainty when providing NDIS services and supports to people with complex care and support needs.

Disability service providers across our region have historically and presently successfully managed the needs of people with complex care and support needs. This is exemplified through local DSPs successfully gaining contracts for, and managing weekend emergency and crisis care for PWD with complex care and support needs for a number of years. Our local disability service providers have expressed strong commitment to continuation of such service provision, but have clearly and rightfully identified that the not for profit sector requires the necessary funding to deliver such specialised care. Such funding may take the shape of increased resourcing within individual NDIS plans for PWD within this cohort, or be provided for through the State in terms of a funding model for which crises expenses are recouped through a rapid claims system.

In addition to high care and clinical support scenarios, people with complex care and support requirements may in some cases exhibit behaviours of concern. In this circumstance, PWD may become suspended from school or a place of accommodation (such as a group home) or employment. In such a scenario, the PWD to support worker ratio is likely to increase in order to provide a higher level of support, with the aim for the PWD to re-enter school, accommodation, employment, etc. In most cases, the individual NDIS plan does not provide for an increase in supports throughout the 12-month plan life, and the PWD cannot gain access to the increased level of behavioural support, case management and supports that are necessary and required to rejoin and participate in their daily activities, until their plan is reviewed, which can take months.

Accessibility of Early Intervention supports for children

There is much evidence that timely diagnosis and delivery of regular and targeted early intervention supports is a vital contributing factor to improving a child's developmental outcomes. Prior to the NDIS, a range of various not for profit service providers across our region delivered supported playgroups, social groups, and therapeutic supports for children with a developmental delay. Our experience over the last 18 months of NDIS implementation across our region is that rarely will a child receive resourcing for non-therapeutic supports in their NDIS plan. The impact of this decision on both the early social skills and coping

mechanisms of the child, and the impact on the carer/family members in not having readily available access to informal peer support and short periods of separation/break from their child has been devastating.

Interchange Illawarra, a local disability service provider has identified the significant challenges they have experienced in the provision of services and supports to children with Autism, and their carers, as a result of the implementation of the NDIS. Interchange Illawarra identify the dramatic reduction in participation of the highly successful 'Saturplay' program, targeted at children on the Autism Spectrum, who often exhibit complex needs and require substantial supports. Prior to the introduction of NDIS, Saturplay operated from two separate sites, and had a wait list of three years. Now with non-therapeutic supports receiving little if any plan resourcing for children, the Saturplay program operates out of only one site, and carries vacancies.

In terms of accessing therapeutic supports that are funded in individual plans, families in this region are commonly waiting in excess of 12 months to gain access to a speech therapist or occupational therapist. Such lengthy wait times to gain access to approved and funded therapy, at such a critical development stage is alarming and neglectful of the system, particularly in the absence of not for profit led supported playgroups and informal peer support meetings and social groups.

It is clear that we are failing our children, children who are already identified as vulnerable and requiring substantial assistance. The impact on the well-being of not only the child with a developmental delay, but also the families/carers in not receiving adequate therapeutic and non-therapeutic supports is significant, with pressures likely to increase in the areas of health and mental health, thus placing further strain on the health care system.

It is important to acknowledge the geographically diverse regions that comprise the Illawarra, Shoalhaven, and further South Coast localities, and that these areas are often most easily accessed by private vehicle. Public transport options across the Illawarra, particularly the northern Illawarra, are considered reasonable by metropolitan standards. However, with the South Coast rail network stopping just north of Nowra, and minimal bus services operating from the Shoalhaven and further South Coast localities, transport is a critical issue for PWD, including children with a disability and their families.

Previously, Community Transport was well utilised by PWD across our region, with many of the children physically accessing the Interchange Illawarra Saturplay service via Community Transport. With the recent introduction of the Point to Point Transport System, Community Transport cannot be utilised to transport children to social support groups, and this has directly affected the small number of children that have been allocated NDIS funding to attend non-therapeutic supports such as Saturplay.

The effectiveness and impact of privatising government-run disability services

The notion of 'privatisation' is somewhat problematic in this context. Privatisation has traditionally meant the transfer of publically delivered services to private for-profit providers, as has been the case with the electricity and telecommunications sectors. With the advent of the NDIS, government-run disability services were transferred to the not for profit sector. The not for profit sector has a great deal to offer participants and their carers/families, as their whole purpose is to maximize outcomes for vulnerable clients and communities, rather than to return profit to shareholders.

There have been some difficulties in the transfer of services to the not for profit sector, however, and these include:

- Lack of resourcing for the transition period;
- Failure to recognise that the funding organisations receive under the NDIS may not be the same as was previously allocated for the provision of the service under the previous block-funding model;
- The difference in the rates of pay for staff previously employed by the public sector who retain their previous award rates and conditions, and those paid to staff of the non-government organisation – often based on the Social, Community, Home Care and Disability Services (SCHADS) Industry Award;
- Some of the legacy issues from previous service provision, such as clients not having any access to community activities, or having out of date plans.

Another issue is the withdrawal of funds for emergency response. When funding is not available to support emergency response, it puts vulnerable people at risk, and has implications for the health and justice systems.

The provision of support services, including accommodation services, for people with disability regardless of whether they are eligible or ineligible to participate in the National Disability Insurance Scheme

Local service providers report an increase in the gap for much-needed accommodation services following the implementation of the NDIS. Some of the key groups who are now missing out on accommodations services include:

- People with a disability who are over 65;
- Children under seven;
- People under the age of 18.

For parents of children and young people who are not being offered accommodation options under the NDIS, the only option is to access the statutory Out of Home Care system, which is typically instituted due to child safety concerns. To have a child placed in Out of Home Care can be seen as failure as a parent, and comes with significant stigmatisation.

The adequacy of current regulations and oversight mechanisms in relation to disability service providers

It is important that regulations and oversight mechanisms protect people with disability but do not impede service provision. We do not want to see a system which stifles innovation due to risk avoidance. It is also important that regulations do not impose additional complexity or over-reporting on DSPs.

For example, one service provider identified that the refrigerator needs to be locked in one of their service sites. This represents a reportable physical restraint. However, it should not need to be noted for every occasion of service – in this case every day. The system should be streamlined to report only once that the refrigerator will be locked for the foreseeable future.

Service providers should also be given a reasonable and respectful period of time to respond to queries or issues raised through the NDIS Quality and Safeguards Commission.

Workforce issues impacting on the delivery of disability services

The Community Services and Health Sector continues to be Australia's largest and fastest growing employer with the vast majority of direct care staff being female. The industry is the largest employment sector in the Illawarra and Shoalhaven, and 35% growth is projected over the next ten years. However, the industry is already experiencing chronic workforce shortages, particularly at the support worker or direct service delivery level.

With the increase of people reaching retirement age, another consideration which arises is the high level of retirement from the health and community services industry. Currently workers in this sector have an average age of over 50 years, with more than half the workforce being 45 years+. This in effect means that there will soon be a significant retirement exodus from the industry. This trend will put increasing pressure on our already strained workforce.

The growth in aged services is also putting considerable strain on the disability workforce. The advent of the Certificate III in Individual Support facilitates the flow of workers between the two sectors, but has so far done little to address the chronic workforce shortage. A recent

survey conducted by Regional Development Australia Illawarra indicated a growth rate in the aged and disability workforce of some 43% over the next three years.

One key challenge which has been identified is the poor public perception about the social services sector and the range of careers and career pathways that it offers. Careers in this industry are generally regarded as very low status, which is augmented by the salary structure and the relatively low rates of pay for workers across all levels, but most particularly at the support worker level. Indeed, it may be argued that the poor rates of pay both reflect and augment the low level of regard in which the industry is generally held, despite its vital importance to our communities.

The sector is also heavily reliant on casual and part-time workers, and the uncertainty of the funding environment after the implementation of the NDIS makes it even more difficult for providers to offer permanent work. Even when permanent work is made available to casual staff, providers report a lack of uptake because many workers prefer the perceived higher rates of pay as a casual because of the loading, to the security and other benefits offered by permanent employment.

Many providers report that restrictions in the SCHADS award impact on rostering, and result in disgruntled staff. It is strongly recommended that some of these conditions be reviewed. Providers also report that NDIS pricing does not leave them with sufficient surplus to invest in staff training or other important development opportunities. This is particularly concerning when the lack of staff is resulting in the employment of people with no skills or qualifications, and no experience working with people with disability.

Challenges facing disability service providers and their sustainability,

There is no doubt that the implementation of the NDIS has brought with it severe challenges for many disability service providers in respect to their viability and sustainability into the future. Many providers are reporting significant amounts of unpaid and unbillable staff time to support carers to understand and to navigate the system.

Organisations which are funded to deliver support coordination advise that the hours allocated for this vital service are most often inadequate for the amount of support required, and that these hours are now being cut from subsequent year plans.

Service providers who operate over multiple areas advise that locational and situational disadvantage is being reflected in plans. People from low socio-economic areas are clearly at a disadvantage when it comes to self-advocating for what they, or the person they care for, need.

NDIS pricing is a key barrier to organisational sustainability, and the issue of pricing is even more fraught in rural areas. The NDIA have implemented a price increase in acknowledgement of the challenges of rural service provision, but the implementation of the price increase adds transactional complexity. Rather than increasing the base price per hour by a percentage amount to allow for a higher unit cost in rural areas, the new arrangement allows providers to dig into participant plans to allow a greater part of each individual shift to be billed for transport and travel time. For personal care where shifts are already often short, these now need to be “chopped up” further into different billable rates and items. This increases the number of transactions, requires further rostering, adds complexity to the business model that sits behind their billing system, and increases the already heavy administrative load.

The other compounding factor in individual supports is that they often represent small monetary values that can be claimed for each shift. When claims errors occur, which they often do due to issues in the portal, providers tend to chase payment for larger amounts as their first priority. Significant amounts of accrued income due to hundreds of smaller claims errors are often written off because the costs of rectifying large numbers of small value errors is often higher than what can be retrieved.

Case in Point

A major sustainability concern amongst the disability sector is with the price point for one-on-one supports. The price point is particularly problematic for in-home personal care supports which are generally rostered in shorter shifts - hence contributing to the transactional costs of rostering and billing. Many providers are seeking to exit the market over time or reducing their exposure to non-profitable elements of the rate card which leaves participants with high support needs searching for good quality alternatives.

Traditional providers cannot compete with “platform based” services where people can hire their own worker. However, these service providers can spend up to \$2,000 per direct care worker on on-boarding and induction, training and supervision because they value staff who are capable of managing complex care including people with behaviour support needs and those with complex physical supports or who are medically frail.

While the NDIA has applied an interim 2% increase this financial year to acknowledge these issues the price point remains too low for long term sustainability.

There is a strong perception among service providers that there is a huge variety in the quality and skill level of Local Area Coordinators, and a lack of consistency in Planners. It is

unconscionable that the quality of a participant's NDIS plan is dependent on the luck of the draw as to the quality of LAC and Planner in drawing up and assessing the plan.

It is particularly concerning for PWD and their carers/parents that in an environment where income is strained, organisations will be forced to make choices based on risk and remuneration. Although significant services are provided by not for profit providers, these organisations cannot operate at a deficit.

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

There are many areas where individuals can 'fall through the gaps' between state run services and supports available through the NDIA. In particular, there needs to be agreement between the State and Commonwealth regarding responsibility for health care supports, particularly as related to complex disability non-medical treatment. The current situation leaves providers managing unacceptable levels of risk without assurances of adequate resourcing from Commonwealth or State.

Case Study

A service provider reported the case of an NDIS participant who is a C5 quadriplegic with type 1 diabetes. This person has no movement in the upper body and is therefore unable to administer their own insulin. This person has had diabetes for approximately 40 years, and prior to their injury 10 years ago, was able to manage their own condition. This participant is completely competent to make decisions around the amounts of insulin which need to be administered, their diet etc. The only issue is the inability to self-administer.

The NDIA consider this is a health problem as it relates to a health condition, health consider it a disability issue, as the disability is preventing self-management of diet and the self-administering of insulin.

NDIS has funded 'training for support workers', however they have found that disability providers are only willing to have an Enrolled Nurse or Registered Nurse administer insulin, and will not allow support workers to do so, even after training through the diabetes centre. The impact of this is that care providers want to charge the participant nurses rate, but the NDIA will not fund this because they see it as a health issue. Furthermore, even if there was funding for an EN or RN, there are not enough working in the community to accommodate seeing this client twice daily.

Currently this person relies on a friend who drives 20 minutes to administer insulin twice a day.

The intersection with mental health services and the justice system, is also complex and requires a special focus. People with disability who exhibit extreme behaviours often find themselves dealing with police, and in many cases, are incarcerated when their behaviours would have been dealt with more successfully in the disability service system. Similarly, PWD who experience episodic mental health crises or suicidality, often end up in mental health services.

As previously highlighted, managing the intersections between disability support and state funded care and protection is particularly challenging for younger people requiring residential care to support the management of disability needs. The interaction of these young people with the statutory out of home care system places strain on the system, but most importantly, on families and young people.

Finally, touch points between state operated transport and education systems and the NDIS require clarity. More publically available advice is needed for providers and participants caught in the middle of disputed accountabilities.

Policies, regulation or oversight mechanisms that could improve the provision and accessibility of disability services across New South Wales

Plain English policy and a transparent regulatory framework is urgently needed as providers, participants and families receive highly variable and often conflicting advice from different staff and offices of the NDIA. Current access to operating guidelines for participants and providers is limited, inconsistent and complex. This creates challenges for providers attempting to deliver great outcomes.

Transparency around operational guidelines and principles would assist providers to shape their business models to the expectations of the agency.

Another issue raised was the disparity between the level of compliance required from registered providers compared to non-registered providers. There is general agreement that the NDIA should set high standards to maintain quality services for people with disability, and recognition that many long-standing providers who are now registered under the NDIS have operated in this way for decades.

However, non-registered providers are not subject to the same level of scrutiny and do not have the same constraints regarding the Price Guide. This in effect means that the NDIA's new competitive marketplace approach has created two marketplaces: one which is subject to all of the legislative and compliance obligations of being a registered provider without being funded to meet these obligations, and one where there is a free market open to all non-

registered providers who only have to comply with minimal requirements e.g. only being required to adhere to the Code of Conduct).

Any other related matter.

Employment as an Option in Plans

Many NDIS plans locally lack employment as a goal. Work offers huge value to people with disabilities including improved self-esteem and wellbeing, social inclusion and personal and financial reward.

Quality of Plans and Second Year Issues

Providers report significant variability in the quality of NDIS plans due to lack of consistency between individual planners and LACs within each office, and even more significant variations between different regions.

The requirements for documentation from families can be extensive, providers and carers are now reporting that, in second year reviews where we expected the process to be simplified, they are instead seeing requests for more and different documentation which is placing stress on families and providers. There is a continual fear of “clawback of funds” amongst families, and many older parent carers who had thought their care arrangements were in place and safe for their son or daughter “for life”, are once again feeling the need to advocate strongly in their old age.

Case Studies from Australian Disability Employment Provider

Employee ‘A’ (female 45-55 years old with moderate intellectual disability and no supports beyond ageing mother)

‘A’ was adopted as a baby with no medical records. As a toddler, it was established that she had an intellectual disability. She then went through the ‘special school’ system and then onto the Disability Support Pension (DSP) through Centrelink.

‘A’ had always used her family GP for many years until his retirement some years ago, and subsequently just utilised medical centres for general visits (colds etc.).

In 2017 ‘A’ was assessed as eligible for the NDIS and received a plan.

For her 2018 review she was advised that ‘undiagnosed intellectual disability’ was no longer acceptable to the NDIA. This immediately created considerable anxiety for ‘A’ and her mother.

The service provider made numerous phone calls advocating for 'A' and was given conflicting information from the NDIA and Uniting LAC , with one opinion being 'A' would need to be diagnosed by a clinical psychologist before being eligible, and the other opinion being 'A' would need to be diagnosed by a GP before being eligible.

With the unremunerated support of the provider, they were able to locate a GP who had seen 'A' several times in the previous 3 years and the provider was able to submit some evidence to that doctor. The GP, after conducting his own assessment and considering the supplied evidence, was confident to provide a medical report stating 'A' had a moderate intellectual disability.

The NDIA accepted the GP report and provided 'A' with a plan, however this was only after 'A' and her mother experienced weeks of concern, distress, anxiety and uncertainty. Neither 'A' or her mother now have any confidence or trust in the NDIA.

Employee 'B' (Male 40-50 years old with moderate intellectual disability, developmental delay and mental illness, with no supports beyond ageing mother)

Whilst 'B' was at work awaiting his first NDIS plan there was an incident where 'B' demonstrated aggressive (verbal) behaviour towards another supported 'X' at work as a result of the other person calling 'B' a paedophile as a joke. It transpired that the other person didn't know what 'paedophile' meant, but he knew it was a 'swear word you used when you wanted to insult someone'.

Speaking with 'B' about his subsequent threatening words towards the other person, he disclosed a traumatic childhood and why that term angered him so much. The provider arranged for, and paid for counselling for 'B', and noticed a positive change in his behaviour.

Sometime later 'B's brother committed suicide and 'B' (against advice) returned to work a few days after the funeral. Without provocation 'B' physically assaulted 'X' and although there were no injuries as a result of the assault, the provider terminated 'B's employment.

Some weeks after he finished work, the provider was contacted by 'B's mother who was very distressed and advised that the NDIA had told them 'B' is not eligible for the NDIS because he 'only has a mental illness and the NDIS doesn't cover that". She stated that 'B' was suicidal. Over the years the provider had developed a trusting relationship with 'B' and he had asked his mother to call them to see if they could help.

After extensive inquiries it was established that 'B' would need some form of medical evidence establishing that he had a disability. Luckily 'B' was already under the treatment of a Psychologist addressing other issues and he was able to obtain sufficient medical evidence.

The provider assisted 'B' in his subsequent NDIS plan with a Uniting LAC and 'B' was much happier and responding positively to his mental health treatment to the extent that the provider agreed to his request to return to work when his plan was approved.

However, 'B' has now received his approved plan and whilst work in supported employment is a goal, it was not funded. This news has devastated 'B' and his mental health has taken another serious decline and he is once again suicidal.

'B's' issue remains unresolved, neither 'B' or his mother have any confidence or trust in the NDIS, nor will they communicate directly with the NDIA.

Employee 'C' (Male, 50-60 years with no informal supports, he has worked at the ADE provider for nearly 40 years)

'C' resigned last Monday because he can no longer handle the stress of dealing with the NDIA. Once again, this person who has a moderate intellectual disability and developmental delay cannot establish his eligibility because of a lack of medical evidence.

'C' was initially accepted into the NDIS in 2017, but now at review time, he was advised that 'unspecified disability is no longer acceptable.' The ADE provider, and the Illawarra Advocacy Service made extensive contact with the NDIA and ultimately they agreed to do a review. 'C' completed his review and was asked at the time if he wanted a 12-month or 2-year plan. He requested a 12-month plan.

He has since received a 3-month plan with no funding for supported employment (regardless of the fact he told the planner that all he needed was transport assistance and funding to work).

On examining 'C's' plan, it was revealed he has been allocated \$250 for community inclusion activities and \$1000 to complete the clinical psychologist assessment. This was not discussed with 'C' and he had no idea what the funding was for. Essentially he has been given a plan extension pending his medical review.

He subsequently made inquiries with his doctor and got a referral but has since found out that the assessment will cost at least \$2000. He cannot afford the additional \$1000. 'C' heard that the University of Wollongong is undertaking the assessments for \$1000, however there is a 6-month waiting list.

To quote the service provider "Words cannot describe how distraught & dejected 'C' was in my office on Monday when he resigned. He stated he will just go back to being on the DSP and staying home. He continually referred to himself as useless and stated that the NDIS 'doesn't give a shit about him'."

The provider is still advocating for 'C' (unfunded) because they are very concerned about his emotional wellbeing and safety.

The Portal remains a major issue and is a major administrative burden on organisations. Services providers advise there is no way to integrate their internal systems with the Portal to automatically retrieve basic data such as the NDIS number, Plan ID, Plan start and end date. The only way to reconcile this is to go into the Portal and search each individual participant, then go into each individual service booking to manually capture the information and enter it onto a spreadsheet to be checked against records. This 'system' is clearly cumbersome and unfeasible.

For three consecutive years there have been failures in the NDIS Portal at the start of each financial year. In 2016 the new portal failed altogether, in 2017 the indexation to rates for providers was unable to be claimed and this was not rectified until the following January 2018.

This new financial year, in the course of implementing price increases the NDIA made changes to service bookings on the portal which resulted in thousands of service bookings for stated supports (line items) being ended and recreated by the NDIA. This meant that for many clients, insufficient amounts were left in service bookings in the previous financial year. This meant that service providers claiming within NDIS time frames, were unable to claim the amounts owed for services already delivered. The solution offered by the NDIA, was to propose that the many thousands of claims, some for service episodes as small as a couple of hours of staffing support, needed to be manually claimed. This again represents a huge transactional cost to those affected providers.

Where there have been industry wide problems in the portal there is no advice to providers as to what has occurred, no acknowledgement of the issue, or a time frame to fix the issues and no timely recommendation to providers as to how they should proceed.

Recommendations

1. That the State provide further policy development, guidance and enablement of successful NDIS implementation and wider community inclusion, through the continuation of funding for advocacy, capacity building and support for both PWD and their carers.
2. That the NDIA trains planners and LACs to deliver consistent, quality plans for clients regardless of location and to better assess employment goals, encouraging options wherever possible for participants to gain employment skills or be supported to directly enter the workforce.
3. That the State respond to the urgent need of the wider NDIS service market development, together with the development of a state-wide education approach and commitment to training disability support workers, such as promoting the utilisation of traineeships.
4. That people with complex needs and support requirements have individual NDIS plans resourced with crisis funding that can be accessed to deliver reasonable and necessary supports for PWD that are requiring higher level of care due to an extraordinary event (e.g. medical, mental health, behaviours of concern).
5. That the not for profit sector is sufficiently resourced and funded to continue to provide high level care to people with complex needs and support, and that the case management services that are currently being provided in many circumstances be acknowledged, with a commitment to funding ongoing case management of people with complex care and support needs.
6. That children of any age have the reasonable and necessary therapeutic and non-therapeutic supports they require to improve their developmental outcomes. This should be reflected in the resourcing of individual NDIS plans.
7. That the State provides resources to enable the not for profit sector to resume the delivery of supported playgroups and peer support networks to children with a developmental delay/disability and their families and/or carers.
8. That the State investigates the constraints and impacts of the newly introduced Point to Point Transport system as a matter of urgency, particularly with regard to the use of Community Transport for all PWD (including children) in accessing funded NDIS supports.

9. More work is undertaken to determine the lines of cross over in policy and approach between the NDIS and state government provided services, and to clearly identify accountabilities.
10. Urgent development of public policy and operational guidelines, preferably with stakeholder involvement, to ensure that implementation is feasible for providers and understood by participants.
11. That the NDIA ensures that changes to the portal and systems upgrades are run in a test environment and monitored for unforeseen adverse errors prior to going live nationally.
12. That there is better communication around known errors when they emerge. This is especially required when providers are left without reimbursement for services already delivered. In relation to sector wide portal problems, communication of expected time frames to rectify issues, or advice on alternative work-arounds is required for providers to recoup amounts owed.

I would like to thank Portfolio Committee No. 2 – Health and Community Services, of the Legislative Council for providing CI Group with the opportunity to raise the above-mentioned issues and concerns, and look forward to engaging with the Committee in the further discussion of, and resolution of these issues. Should you require further information on any of the points raised in this submission please contact me on _____ or email at _____.

Sincerely,

Nicky Sloan
CEO