

Submission
No 226

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

Organisation: Paraplegic and Quadriplegic Association of NSW (ParaQuad
NSW)

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Hon Greg Donnelly
MLC Chair Portfolio Committee No. 2 –
Health and Community Services
NSW Parliament
PortfolioCommittee2@parliament.nsw.gov.au

To the Hon Greg Donnelly MLC,

Re: ParaQuad NSW response to the inquiry into the implementation of the National Disability Insurance Scheme (NDIS) and the provision of disability services in New South Wales.

ParaQuad NSW has been providing supports to people with disability to facilitate living and participating in the community for over 57 years. As a not-for-profit organisation started by people with disability for people with disability, ParaQuad has offered a range of community-based services for people with spinal cord injuries (SCI) and like disabilities over this time. Providing clinical and therapeutic supports such as advice on continence, managing the complications associated with SCI in the community, advice and support on the best equipment and home modifications to support a full life. ParaQuad has provided therapy and offered training to support individual participation goals as well as operating a specialised Attendant Care Service for over 30 years, a 24-bed specialised SCI accommodation facility at Lidcombe NSW with ten independent living villas on the same property.

In addition, ParaQuad established a community-based health products business, BrightSky Australia, providing consumers with a comprehensive range of continence, nutrition, wound and skin maintenance products, conveniently delivered to the home across Australia.

ParaQuad NSW has been working with the NDIS since the beginning of the trial phase in the Hunter and now together with BrightSky Australia has many thousands of participants across Australia and hence is able to comment authoritatively on both its experience with the NDIS and that of participants. Under the NDIS we provide several service types to support participants to achieve their goals:

- Attendant Care (Personal Care)
- Supported Accommodation
- Short-term accommodation
- Highly specialised Nursing (assessments, intervention and training e.g. neurogenic continence assessments)
- Occupational Therapy (Assistive Technology, Home Modifications, Direct Therapy)
- Coordination of Support (conducted via Peer Support)
- Social Work
- A comprehensive range of health products

Whilst there are challenges associated with any worthwhile reform, we have set out responses to a number of points listed in the Terms of Reference of the Inquiry below:



(a) The implementation of the National Disability Insurance Scheme and its success or otherwise in providing choice and control for people with disability:

Choice and control is essential and is welcomed, especially for people with disability who have felt in the past they have not had the ability to make decisions about their supports. The concept of person-centredness being at the heart of planning for participants is critical to achieving goals and outcomes.

Despite this positive framework and participants welcoming the opportunity to voice their goals as the director of their supports, there have been difficulties in the implementation of the planning process to ensure that the participant remains at the centre of their planning and budget.

Participants report that they find that there is insufficient time for the planning process and that their voiced goals are not the goals that come back to them in approved plans. They report that they feel they are not informed as to what their choices are, which can be disempowering for those with less knowledge. The processes are reported to be daunting, and the resources and supports available to participants to assist them to understand the processes and make choices are limited, and spread across too many roles.

Participants are required to negotiate a plan with a Local Area Coordinator (LAC), receive back a plan from a planner who is unknown to them and generally inexperienced in dealing with SCI issues, and then access a Coordination of Supports (COS) person to help them make sense of the plan. In most cases, this requires explaining and coordinating life choices, goals and needs to three separate people/services, additional requirements that participants did not have to do under previously State funded systems. It should also be borne in mind that this difficulty is being experienced by participants who were fortunate enough to have had a State funded plan and are now transitioned to the NDIS. However, for those participants with SCI who have in fact never had a previous funded plan, they find the process especially daunting and confusing particularly when dealing with LAC who do not understand the complexity of SCI and the original proposed plan is returned changed. Some participants find this whole process confusing as to whom they should approach when they have questions or concerns regarding their plan or their budget. This confusion has also been observed to slow down responses to urgent situations.

In addition, participants report that their plans were changed without their request following the planning meeting, or after a plan review. The execution of the plans appears less person-centred and goal oriented than the ideals of the scheme, with many participants reporting that the goals in the plan were not the goals they articulated.

Review and evaluation processes are little understood, and little information is available on how decisions are made, or budgets set. The portal does not sufficiently delineate the funds to assist participants in understanding what their funds should be covering.

The difficulties in understanding the plans, the portal and the planning process are magnified by the unwieldy communication systems. Service providers or clinical prescribers under the system get little or no feedback, causing unnecessary, time consuming attempts at liaison to obtain conflicting information. Participants report they avoid contacting the NDIS to find out information, due to frustration at not being able to access the information they need, or speak to their actual planner. In our experience, planners don't always respond to requests for contact or information from providers either.

Unnecessarily complex divisions between Health and NDIS systems cause confusion and inequity based on region and participant ability to self-advocate.

In terms of the broader communication of the NDIS with the community, as a service provider we are still receiving referrals from eligible participants who have not yet enrolled in the NDIS or have not heard of it. We have had people with spinal cord injury who reported that they were overwhelmed by the system and are choosing not to participate for that reason.

Suggestions for point (a)

- Feedback system for clinicians re the status of the approval process for participants.
- Communication system simplified for participants.
- Portal to provide detailed plan and budget information to empower participants.
- NDIS to ensure participants are aware they are self-managed as many are not aware until they contact providers.
- Detailed feedback to be provided for declined items to support appeals.
- Clear guidelines for providers on how to best work with self-managed clients, agency- managed and all of the combinations of options.

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

People with complex care and support needs, such as SCI have in the past learned to use a suite of services to assist them to plan and achieve their goals. Whilst the NDIS aims to provide a singular base from which participants can plan and direct their own life, it causes difficulty for the person with complex needs.

It has been observed that the first plan for a person with a newly acquired spinal cord injury in hospital now has support from the rehabilitation team which has improved that planning process, and the participation outcomes. Subsequent plans still cause confusion. Other participants express frustration that they don't have enough funds to choose to have either a report or the presence of a multidisciplinary team member to assist the direction of a complex plan to minimise the complications of their disability and achieve maximal outcomes.

In reviewing plans, it appears that planners fit participant's needs into categories rather than recording and understanding individual needs. The goals are not in the participant's voice, and they frequently report are not reflective of their stated goals. The processes are very unclear, and participants report feeling uncertain about making future plans due to the changes to their plans. We have observed plan review for assistive technology or other requests, anecdotally resulting in decreased care budgets. Consumable budgets are not increased following clinical assessments making recommendations to increase, such as after the provision of a Continence Assessment.

Participants are recommended to access services that are geographically the closest, rather than most appropriate. With the new travel restrictions, participants are powerless to make a choice around choosing a provider that specialises in their needs, as they may find they are unable to get that service provider to travel to the participant's location to conduct the assessment.

There is inequity in the system, due to the individual decision making power being in the hands of the planners, without transparency of guidelines or decision making to the participant or the provider. For example, the same assistive technology request, for two people with a similar disability, need and goal with the same provider supplying the report. Where there is a different planner, one may be approved and one declined. Declines can come with little or no explanation, leaving the participant powerless in appeal, and advocacy from a provider difficult. It should also be noted that scripts for assistive technology (i.e. a powered wheelchair, essential for most people with SCI) are prepared by a professionally trained clinician, an occupational therapist, after many hours of examination and analysis of a participant's needs. It is therefore incomprehensible that an inexperienced planner, a non-professional, could make a determination and decline a specific request.

An example of this ludicrous situation was when one planner questioned a script for a powered wheelchair for a participant due to its cost stating he had seen something cheaper in eBay!!

After lengthy delays for approvals, equipment is ordered but funds may have been drawn down (i.e. not quarantined) before the participant and provider can confirm this is still best equipment. As participant's needs can change, this can lead to expensive equipment being incorrectly purchased.

Suggestions for point (b):

- Communication pathways to be published on the website (including appropriate contact details for area offices)
- Prescribers to be notified of approvals or declines directly.
- Separate communication pathway available for urgent matters.
- KPIs for planners to respond to certain types of requests.
- Clear and transparent system for equipment required for clinical urgency (whether funded by NDIS or Health).

- Travel allowances to be increased for participants with identified complex needs to access a specialised service.

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

There is an increasing accountability of services, and a sense of empowerment in some participants to request what they need and when. Participants that previously received services such as therapy/accommodation directly from government (ADHC) have increased choices.

Some providers are withdrawing from NDIS, causing a loss of skillset in the disability sector. For example, some HACC home modification providers have been refusing to provide quotations for NDIS work.

NDIS funds may be less flexible than Community Support Program (CSP). In the past, CSP funds have been able to be accessed for participants with complex needs to fund assistive technology or minor home modifications that would facilitate the provision of an attendant care service, for example to address a work health and safety issue. The lack of responsiveness of the NDIS system to respond to assistive technology or modification requests can lead to personal care (attendant care) services having to withdraw supports, potentially leaving the participant at risk of being left in bed.

Suggestions for point (d):

- A separate system for situations of urgency, or where there is a risk to the participant's access to services, or a significant potential health risk.

(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 National Disability Insurance Scheme,

Community-based prevention and/or management of pressure injuries for NDIS participants with SCI is a critical service. NDIS will fund preventative equipment, but sees the management of wounds as primarily a Health service. With many Community Health services focusing their services towards people over 65, this can lead to a gap. ParaQuad NSW is a community-based organisation that offers substantial supports in this field, both in preventative work (offering pressure mapping, support surface advice, skin care routines) and management (wound management dressing and plans, advice on products, pressure mapping, adjusting positioning to alleviate pressure, etc.). In the interest of participants' wellbeing, continuation of this service results in an unnecessary increased cost burden to ParaQuad. It should be noted that ParaQuad providing this service reduces hospital admissions and aids re-entry into community participation (Middleton, 2012).

There are significant complications for people over 65 with a complex disability. The Federal Aged Care system is unable to provide even basic care, let alone when combined with therapeutic and clinical supports, Assistive Technology, home modifications and consumable needs. The Aged Care system is ill-equipped to assess and interpret needs for people with complex disability, as their expertise lies with ageing in the general populace.

It is important to recognise that across Australia, many people with SCI were over 65 years of age when the NDIS was launched in their area. Historically people with newly acquired SCI were encouraged to be as independent as possible when they left the hospital setting and consequently utilised partners/ family members to provide assistance with care and did not access state funded systems. These people have aged and are now requiring assistance; however as they did not have any State funding their only recourse is the Aged Care system which does not provide basic care for people with SCI. So compared with those under 65 this group are significantly worse off and clearly an inequity exists. Currently ParaQuad is liaising directly with the Minister for Aged Care to rectify this imbalance and is strongly advocating for a significant increase in the Aged Care supplements to provide at least \$150,000 per annum to those with SCI aged over 65.

There is an issue with accommodation facilities that ParaQuad has experienced as a provider. There is a basic lack of understanding of the SCI condition and the level of care some people require. The bureaucracy has determined that people with SCI should live at home if possible or in a group home of 5-7 persons. They exclude the concept of a slightly larger facility to support people who require 24x7 care. This type of facility is considered "institutional" and conforms to a medical/hospital model despite the fact that many people with SCI require this type of facility or would choose this sort of facility. Objections put forward are that such a facility reduces "capacity building" in that the individual is provided with prepared meals and that cleaning and laundry is provided are typical comments! They have closed minds to the fact that

some people with SCI are unable to cook or prepare meals let alone clean and do laundry. Such comments portray a disturbing ignorance and is accentuated when offers to visit such a facility are declined and hence the opportunity to speak with residents and understand just what a community environment exists and why people should have the “choice and control” to select such a facility if required.

Currently there is debate within the NDIS regarding the level and extent of funding for ParaQuad’s Ferguson Lodge facility at Lidcombe, NSW, because it does not conform to the Supported Independent Living (SIL) guidelines, which are the legacy of previous State ADHC thinking. There is a level of hypocrisy here when considering someone with SCI under the age of 65 is not supported to live in a more “institutional” support facility but someone with SCI aged over 65 requires care and not being able to benefit from provision under the NDIS has as the only recourse the Aged Care benefits and “institutional” aged care accommodation. As the maximum they can obtain under Aged Care funding is around \$49,000 per annum which is insufficient to live at home, they are recommended to go and live in an aged care facility. As is well known, these facilities house on average in excess of a hundred people. Is this not an institution? But, even then, these facilities cannot adequately cater for someone with SCI. The degree of one-one care that is required is not available, nor is the expertise, and the morning bowel care routine for someone with SCI could take two hours!

Under the NDIS incentive scheme to facilitate the construction of suitable accommodation for people with disability, Specialist Disability Accommodation (SDA), there is no provision for capital to be made available unless either a group home (up to 5) or units of 7 are built on a property. Therefore to build a 24x7 facility of say 10-12 people with a commercial kitchen and laundry would be at the developer’s risk and for participants to decide to live there would require they have approval for SIL funding. This is the current debate which to date is unresolved.

Suggestions for point (e):

- An additional supplement in the aged care system for people ageing with a complex disability such as SCI to enable them to live at home if desired with annual support of at least \$150,000 p.a.
- Revision of the SIL NDIS program to better reflect reality of costs and choice for people with SCI.
- Revision of the SDA guidelines to facilitate capital funding for specialised accommodation of any size.
- Clear, articulated and consistently applied delineation between NSW Health and NDIS responsibilities.
- An understanding that prevention and management of disability-related health needs in the community supports both community participation for people with disability, and reduces ongoing health costs and hospital admission. This should include funding for services that sit in between health and disability.
- Government Departments to work co-operatively and focus on resolving issues for the participant and not say “that’s a health issue”, “that’s a disability issue”.

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

The NDIS providers register is vague and difficult to find appropriate service providers for participants. There is no delineation of clinical expertise, or areas of practice of services. Previous ENABLE guidelines specified levels of experience required by assistive technology prescribers. NDIS has no equivalent systems, and has been observed to take prescriptions provided by assistive technology suppliers which would appear to be a conflict of interest.

(g) Workforce issues impacting on the delivery of disability services,

Much has been written about the workforce requirements of a fully rolled out NDIS. Figures often quoted suggest that the additional workforce required could be well in excess of 25,000. This seems an extraordinary estimate given the fact that people with a severe disability are today being supported by family or friends. Whether or not they have a care package is irrelevant. They need support and most likely family is providing it. So it seems logical to state that in fact the “workforce” is already there. The issue is should family or friends be paid?

If one considers the “choice and control” principle of the NDIS, why is it that a participant cannot elect to have a paid independent personal carer say during the week and have family paid during the weekend? Or for that matter, just pay family members in lieu of previously unknown personal carers? Family would have been supporting the participant prior to the NDIS, are familiar with special needs and are there generally 24x7. Arguments offered about not paying for family care centre around “changing the relationship from one of a family member to one of “employer/employee””; another is

the possibility of “fraud”. Both these arguments we believe have no foundation and ignore the reality of how disability is being managed in the home environment today and thus why additional workforce of this magnitude is forecasted.

Planning for workforce is difficult as statistics on, for example, where people with SCI are located are scarce. Once people apply and are accepted into the NDIS means they surface perhaps for the first time so workforce planning is reactive. Requests have been made over many years for statistics to be released but due to privacy issues have not been readily available.

It is difficult to predict throughput of work and timeframes with the NDIS for clinicians. This this makes it difficult for us to correctly plan staffing around community demand and needs. There is a great deal of frustration and poor work satisfaction reported amongst clinicians working with the NDIS, as they receive little or no feedback, and appear to have their submissions approved or rejected on different bases.

Rapid explosion of workforce can lead to poorer quality of services. Services that have an emphasis on quality, or use resources to advocate or support participants to navigate the new systems are financially disadvantaged.

As an organisation ParaQuad provides services across the lifespan. It is difficult to sustain this approach and offer the same specialised services to participants over 65 due to the inequity of funding.

Suggestions for point (g):

- NDIS to have performance indicators on responsiveness to requests for Assistive Technology or Change of Circumstances submissions etc.

(h) Challenges facing disability service providers and their sustainability.

- Fundamental to providing care to a participant is servicing by a personal care assistant (PCA). The wage scales for this group vary according to qualifications and experience. The NDIS pricing for providing care is insufficient for the total recovery of costs associated with providing a substantial PCA workforce which apart from covering wage costs needs to cover accreditation, WHS, carer management, client support, rostering, systems and corporate overheads, some of which may not be applicable for small providers.
- Attracting an appropriate workforce, with workers who have the right values and attributes remains a massive challenge.
- Price increases for personal carers do not adequately cover the associated department operational costs as well as head office/corporate costs of operating a care service. There seems to be an assumption that participants will self-manage and employ their own carers. This is not the case and therefore does not provide sufficient funding to cover administration and compliance requirements.
- The preoccupation of the NDIS with fraud is no clearer demonstrated by the construction of the elaborate Price Guide and Portal. In the first instance people with disability generally have poorer IT skills than able-bodied person yet are expected to negotiate the unresponsive portal. The system has been designed to try and eliminate fraud and is therefore complex both from a participant’s viewpoint and as a provider. ParaQuad dealing with many thousands of participants across the country can attest to the long delays in confirming a service booking on the portal and this long delay is with just 160,000 participants currently in the NDIS. The expectation of delay with 430,000+ participants on board is frightful. Additional workforce has been required to address the cumbersome and slow portal issue and poorly developed plans for many participants.
- Choice and control relies heavily on the appropriate allocation of funding within the plan; unfortunately, the inexperience of planners means there is gross inconsistency within the SCI cohort. The lack of willingness of the agency and LACs to engage with SCI peak bodies to assist in education and support with respect to the lifetime needs related to SCI is concerning.
- NGOs should not be expected to provide services that were previously provided by HACC and Health.
- The experience of some of our members with respect to planning and reviews has been good at times (occasionally, they get more than they expected); however, we have reports of Planners not listening to our members and basing plans on assumptions, or, where they appear to listen and acknowledge the issues, the resultant plans or plan reviews are nowhere near reflective of what was discussed.
- Planners sometimes don’t ask our members what their goals are.
- Plan reviews are taking too long. It seems unreasonable to have plans reviewed annually when for most people with SCI changes will occur over time but a plan validity of two years would simplify the system and reduce the NDIS workforce demands.

- Members report that they attend a meeting which they didn't know was going to be their planning meeting.
- Time lag between planning meeting and receiving a plan is often too long (> 3 months).
- Planners use a pre-determined script without taking into account who they are talking to, which means that irrelevant and inappropriate questions are asked.
- Access to emergency funding, previously available by negotiation with the state is no longer available.
- Rules and application of funding with respect to provider- incurred travel expenses is inconsistent and poorly understood by Planners and LACs – providers are being blamed for refusing to claim funding when it would be inappropriate to do so; NDIA acknowledges this confusion but is yet to do anything about it.
- Sustainability will be compromised by slow planning approval, portal system issues, self-managed participants not paying invoices, pricing issues and perceived preference by state government for large providers to dominate.
- Lack of supports for participants to learn the system and poor self-advocacy skills for some participants put heavy loads on providers. Many participants are not sufficiently empowered or aware of the details of all of their needs to self-manage or articulate their needs, for example Wicks (2016) investigation of participants understanding of their continence support needs discovered that 85% of respondents did not know how to request a continence assessment or from whom to access this service.
- Disability service providers that wish to support participants' choice and control to use their service must fund travel and advocacy demands.

Suggestions for point (h):

- Consider an NDIS Smart Card with say five broad categories of expenditure that can be used with registered and endorsed providers.
- Improve relationship with planners and removal of the LACs which don't appear to add value.
- Unskilled planners are making judgment calls that are not based on evidence- based practice. Clinicians skilled in SCI making recommendation for people with complex physical disabilities are being questioned by inexperienced and insufficiently qualified planners/clinicians within the NDIS. The NDIS to consult with relevant recognised experts to develop guidelines related to prescription approval process
- Travel should be funded on a time basis, not a kilometre basis.
- Consideration for access to specialist services where reasonable and necessary should be considered.
- Review and extension of the Support Coordination role.
- Continuation and expansion of advocacy services.
- Allowance in budget for clinical supports to include time to liaise with the NDIS or other services as required.
- Recognition of specialty services required for complex physical disability.

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

- People with spinal cord injury are susceptible to a range of complex secondary complications which require supports for management (Sezer et al, 2015). When these secondary complications occur, they have significant negative impact on quality of life (Sezer et al, 2015). With the introduction of the NDIS it is unclear how participants access such supports and from whom.
- Evidence suggests people with a spinal cord injury experience an earlier onset of signs of ageing (Jensen et al 2013), which may require additional supports or changes or flexibility to supports to facilitate continued quality of life.
- Coordination is lacking, multidisciplinary work is limited, leading to decreased efficacy and efficiency, at time impeding getting a timely resolution to a disability goal, or timely goal attainment.

Suggestions for point (i):

- Offering crisis support services for people to assist them to access the services they need at difficult times.
- Need to be able to have funded time to attend case conferences for complex cases where there is interplay between health, mental health and disability.

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

- A global view of an individual's wellbeing is required. The NDIS, Aged Care and Health need to liaise more closely with the outcome for the individual front of mind. The silos that have existed for many years are now accentuated with the NDIS servicing people under 65, Health claiming some services/equipment is the responsibility of the NDIS, and Aged Care inadequately catering for older Australians with disability needs increasing and at the same time ageing as the rest of the population. The need to better articulate and assist individuals and service providers as to the appropriate jurisdictional boundaries (i.e. something is Health or the NDIS) after critically re-examining how best to assist people.
- Maintain a planner- to- person relationship and single contact number rather than needing to liaise with many parties.
- Ability to register for email updates from the NDIS and from NSW Health as policies, relationships and services develop and change with the system.

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