Submission
No 209

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

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| **Organisation:** | New South Wales Nurses and Midwives' Association (in conjunction with the Australian Nursing and Midwifery Federation |
| **Date Received:** | 8 August 2018 |

NEW SOUTH WALES NURSES AND MIDWIVES' ASSOCIATION
AUSTRALIAN NURSING AND MIDWIFERY FEDERATION NEW SOUTH WALES BRANCH

# Submission by the New South Wales Nurses and Midwives' Association (in conjunction with the Australian Nursing and Midwifery Federation NSW Branch)

# NSW Legislative Council, Portfolio Committee No 2

# Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales

**8 August 2018**

Our ref:BH:DR:JPU:NS
8 August 2018

The Hon Greg Donnelly MLC
Committee Chair
Legislative Council Portfolio Committee No 2

**Attention:** Director, Portfolio Committee No 2 - Health and Community Services

**Email:** PortfolioCommittee2@parliament.nsw.gov.au

**Re:** Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales

The New South Wales Nurses and Midwives' Association, along with the Australian Nursing and Midwifery Federation NSW Branch ('Association') are the registered unions (in both the state and federal workplace jurisdiction) for all employees working in nursing and midwifery classifications and roles.

The Association provides both industrial and professional support and representation to some 64,000 members in NSW. This ranges, for example, from the provision of information about workplace rights, providing direct support to members (and representation if necessary) with employers or before industrial or professional courts and tribunals, assistance with appearances before other courts and jurisdictions, as well as negotiating and bargaining on behalf of members with their employers for awards and enterprise agreements.

The above has meant that the Association provides membership and therefore such services to disability nurses working in either the government or non-government sectors, state and federal. From the perspective of our members, the inquiry instigated by Portfolio Committee No 2 of the NSW Legislative Council is both timely and a reflection that it is so very important to get the rollout and implementation of the National Disability Insurance Scheme ('NDIS') right, along with all ancillary support and assistance to those people with disability.

Certainly the Association and its members would welcome the opportunity to provide further evidence, in addition to that contained in our following submission, at any hearing the Committee undertakes. This submission is authorised by the Elected Officers of the Association.

**BRETT HOLMES**
General Secretary, NSW Nurses and Midwives' Association
Branch Secretary, Australian Nursing and Midwifery Federation NSW Branch

# Executive Summary

While the Association has and continues to support the introduction of the National Disability Insurance Scheme ('NDIS'), we do not pretend that it is not without its difficulties. Already it is demonstrating some significant problems in converting a most worthy concept and legislative framework to a practical and effective day-to-day schema that truly delivers independence, choice and control to those people with disability (as well as for their carers/family).

Reports from our members, as demonstrated by the feedback contained in this submission, reflects this. The almost daily media reports on the plight of individual families desperately attempting to navigate the NDIS framework and processes are commonplace. Unless its implementation and approach is truly centred on people with disability, adequately resourced to provide timely and adequate services and support, the productivity to the community, along with the individual dignity it was meant to liberate and unleash, will not be realised.

Further, the decision made by the NSW Government to use the roll out of the NDIS as an opportunity to vacate the field entirely as a provider of disability and accommodation services is one that the Association and its members have rejected from the day it was announced.

This decision has had the real effect of reducing choice to people with disability (a cornerstone of the NDIS philosophy). It has created a situation whereby the current models of care which provide care and support in an integrated way to those in the NSW community with complex healthcare and disability needs will be lost. In the view of the Association and its members, there must be a reliable and accountable public sector option for those people who need it and/or have the most complex health needs.

As part of this decision to exit the disability services space, the NSW Government has adopted an approach to its staff, many who have worked for decades in disability services, with a heartless disregard to their choice, their interest, and their dignity. Despite the best efforts of some managing the transfer of government services to non-government organisations ('NGOs'), and the protections made available to transferred employees by the Minister for Disability Services and the Department of Family and Community Services ('FACS'), a number of these employees - our members - have felt distressed and little valued via this approach and during this process.

# INDEX

## Format of this submission

The following submission by the Association draws upon a number of experiences of members over the last few years, which since 2017 has included the progressive transfer of services, assets and staff from FACS to NGOs to provide disability and accommodation services.

In addition, the Association notified members of the inquiry announced by Portfolio Committee No 2 of the NSW Legislative Council and encouraged feedback to the Association, with the aim of collating and including such feedback in this submission or how they may make a submission directly to the inquiry.

The Association has assembled its feedback in this submission as per the most relevant terms of reference (‘ToR’), albeit some feedback would sit comfortably within several. Accordingly, the Association has not sought to unnecessarily repeat or replicate feedback that straddle several ToR. Rather, it has concentrated on ensuring relevant information and feedback has at least been marshalled once in the submission.

Equally, a number of members gave experiences or examples that were similar in nature, and the Association has adopted the view of ensuring at least one such example is included, and duplication of similar experiences has been resisted. Accordingly, it should not be assumed as a result that such narratives or examples are isolated.

Finally, the Association has taken the view to provide these experiences, in effect small case studies, without identifying the member, location, employer and most importantly, any overt information that may lead to people with disability being identifiable (save for **Appendix A**). In this way privacy has been preserved, it encouraged the participation and receipt of feedback from members, and it will not create unnecessary distress to particular persons with disability and/or to their carers/family.

**Appendix A** to this submission has been compiled by Association Branch Officers on behalf of members working at the Stockton Centre in the Hunter region, which still operates under the auspices of FACS. Rather than fragment this feedback across the ToR, it stands alone as an important companion piece to the difficulties encountered by the largest disability facility in NSW and the erosion of care and support that has occurred as a result of the NSW Government decision to vacate the field - exacerbated by the resultant delays in any transfer of services from FACS to NGOs well beyond the original identified date of end June 2018.

The Association Branch on behalf of members extends an invitation for Portfolio Committee No 2 to undertake a site visit to appreciate the current difficulties, as well as the potential to reinvigorate public sector services to remain at the very least an option of last resort, or the first for those with complex health issues.

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

Promoting individual rights to freedom of expression, self-determination and decision-making is extremely important. Services need to continue to have a person centred focus but also include the carer and families involved with these individuals. Carers and family should be also involved in the decision making process and provided with the relevant information regarding services and support**,** as they often play a key role in the individual's life.

The NDIS system has limitations to the information and processes in seeking support and services. It remains fragmented and is often *hit and miss* with the information provided. This then does not provide the individual and their carers or family information to make a valid, informed choice, thus not giving them real control. Carers NSW has recommended "*that the NDIA and the NSW Government improve the availability, consistency, timeliness and accessibility of information provided to people with disability and their carers in NSW regarding the NDIS".*[1]

Feedback received by the Association reflects this challenge. Members of the Association have noted their own difficulties as registered health professionals navigating the current system when attending to the needs of their own family members with disabilities. If health professionals and clinicians find the system daunting, one can readily appreciate the difficulties confronting those with a disability and/or their loving family members who have little to no experience of dealing with complex health and disability systems and processes. It does not equate to achieving control or increasing informed choice.

> *"I received a plan but have not been provided any direction or support in how to proceed; 'got funding but have no idea what to do next'. When asked, told need to find provider … have no idea where to start … felt helpless"*
>
> Association member with a child trying to implement their NDIS Plan.

The obligation and expectation must be that communication is in a form, language, and manner that enables people with disability and/or their carers understand the information provided and make known their feelings and preferences. Due to this not being provided it has left gaps in individuals meeting their needs. The choice is limited and restricted by what is now provided by the new scheme.

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[1] *"The NDIS one year in experiences of cares in the hunter trial site. A cares NSW issues paper."* NSW Carers Australia, 2014 (below link) http://www.carersnsw.org.au/Assets/Files/NDIS%20Issues%20Paper%20DSN%20FNL%203%20Oct%2014.pdf

*"My daughter is high functioning and trying to find a provider that can offer what she needs to become independent with living skills has become impossible. She does not want to do group classes. The new NDIS is found to offer less choice than before"*

Association member's experience

These difficulties with the NDIS and its processes are also reflected in feedback from members who work with NGO providers following the transfer of such services from FACS.

The process *"… started … for one resident to get a new bed and specialist wheelchair* [in 2016] *… it was followed up by meetings with family and our Occupational Therapist … submitted a request for these items. despite repeated follow up still has not received what* [they] *need.*

*One thing that happens regularly is - they* [NDIS] *do nothing, we follow up, nothing happens, we follow up again, only to be told that the request has expired and it needs to be resubmitted."*

Association member working with NGO provider (group home)

*"A resident had a wheelchair ordered well over a year ago and somehow NDIS had records of him having an electric wheelchair (*[they have] *never had one of these), they did not inform us of the issue but sat on the request until it was out of date and it needed resubmission; they then expected us to put in a Change of Circumstances form for their mistake. Our Occupational Therapist has been following this up on multiple occasions to no avail."*

Association member working with NGO provider (group home)

[A resident] *"… required urgent consultation by a speech pathologist and dietician to restart them onto oral food … been PEG*[2] *fed for a few months due to illness. When they went to the portal … were told there was not enough money, we asked for a review of their plan which didn't happen for weeks so decision made that the resident would have to pay for the services themselves, then the Trustee & Guardian could approach for reimbursement. Fortunately they* [NDIS] *finally came through with a plan that covered the allied health professionals required for their quality of life to be improved.*

Association member working with NGO provider (group home)

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[2] **PEG** stands for **percutaneous endoscopic gastrostomy**, a procedure in which a flexible feeding tube is placed through the abdominal wall and into the stomach.

*“The whole NDIS system is complicated and difficult to navigate even with help from coordinators, the steps seem to take so long to get through.”*

Association member working with NGO provider (group home)

Certainly a key concern of our members and the Association as a whole, when considering *choice and control for people with disability* was the decision of the NSW Government in 2012 to vacate the provision of disability services altogether, as part of the rollout of the NDIS. (The mechanics and sequencing of this decision and its implementation is dealt with below under ToR (d)).

Certainly the NDIS was predicated, and promoted, as providing choice to people with disability - a framework whereby they were able to exercise a choice as to what was in their best interests and needs, as an *informed purchaser of services*. However, for many, especially those with profound disabilities and/or complex co-morbidities, the complete withdrawal of government operated and provided services, often embedded within a framework of collaborative networks with the public health system, reduced choice and removed the option to remain to have their needs managed via the previous services provided by FACS.

Further, with this exit, a potential exists for consumers with complex healthcare needs to fall through the *gap* created by the complete separation of the provision of health care and social support under NDIS funding. Such needs may not be best served or compatible with the market approach of the NDIS.

While the Association completely supports the introduction of the NDIS, there will be a segment of the NSW community whose complex healthcare and disability support needs are and will be best served under (pre) existing models of care provided by FACS. There must be a reliable and accountable public option and *choice* for those consumers who need it and/or have needs that cannot not be comprehensively managed by NGO providers.

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

The need for maintaining a high level of competence and skill is important in providing safe ethical care. The Association and its members believe that the necessary level of skills and competence are essential on a professional level in providing appropriate disability care. The feedback from members regarding the support in the development, enactment and review of plans has been fragmented. Planning has been provided by individuals with limited experience in disabilities or with no knowledge of the disabilities that are being planned. The greater the complexity the greater the need to have someone with appropriate training and qualifications involved in the planning of care.

This is supported in the research done by The University of Melbourne entitled *"Choice, Control and the NDIS' Service users' perspectives on having choice and control in the new National Disability Insurance Scheme"*.[3] Some participants expressed concerns that new service providers were employing less qualified and less experienced staff to reduce costs and provide a service that was cost competitive.

"*You've got staff with no long term training of any sort. The previous qualification was a Min a Cert IV in Disabilities and now some places are employing people without that qualification. They might have Cert III but a lot of them haven't got anything and they're calling them educator and other names. I don't think that's very good at all, because for someone who's got very rigid routines and autism, I don't think that anybody that's coming in off the streets with no qualifications is going to understand their needs. I know other families feel like that."* [4]

Through this research, concerns were raised that in an individualised system, service providers had increased capacities to exercise choice about which clients they want to attend or to 'cherry pick' clients who are perceived to be more cooperative and compliant and therefore less costly to manage. Due to cost cutting and using less qualified staff, the privatised service providers have expanded the services they provide at the cost to the quality of care. Some government providers have had to withdraw vital services due to not being able to remain competitive within the market. The effect to individuals has been that some have no resultant access to services.

Consideration of factors that drive inequality such as income, education, residential location and household structure remain critical when clarifying opportunities and capacities for individuals, their carers and families to have a choice and control in accessing services and resources under the NDIS.

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[3] *"Choice, control and the NDIS, service users' perspectives on having choice and control in the National Disability Insurance Scheme"*, **The University of Melbourne**, 2017 (see below link). https://socialequity.unimelb.edu.au/__data/assets/pdf_file/0008/2598497/Choice-Control-and-the-NDIS.pdf

[4] Ibid.

In any event, specific experiences relayed to the Association from members provides confirmation of initial difficulties in developing plans, and with subsequent reviews.

For example, during initial NDIS planning meetings in 2016, these are some of our members' experiences.

> *"A huge push to get the eligible person's into the scheme. Very tight turn around for planning for our clients.*
>
> *We had very little to no knowledge of the NDIS (how it worked and how essential it would be for our clients to access services and products). We were informed the initial 2016 plans were to get our clients into the scheme but in-kind supports and funding would remain with FACS who would provide these supports our clients required.*
>
> *Hence initial NDIS funding did not meet the needs of clients."*
>
> Association member working with FACS in 2016

> *"The initial NDIA planners had a varying level of experience; very limited knowledge of: people with complex needs, the NDIS itself; and the planning process …*
>
> *NDIA staff were unable to provide any information requested* [answers to questions]. *They were able to collect information that they had requested, but not able to provide information.*
>
> *Communication was poor, staff had one specific task and that was the only thing that they would do.*
>
> *NDIA staff difficult to contact- would only provide a first name and generic phone number."*
>
> Association member working with FACS in 2016

> *"Plans did not meet the participants changing needs. Assistive technology / equipment not identified in the initial plans and continuing extended plans."*
>
> Association member working with FACS in 2016

The transfer to NGOs exacerbated the issues via plans being extended to accommodate delays in such transfers.

*"Due to the pending transfer of FACS accommodation services to non-government sector, participant plans were extended for varying periods, twice over the last 18 months …"* [at our facility].

Association member working with NGO provider (group home)

*"The funding received* [initially] *in 2016 was insufficient and the funds that were calculated pro rata for extended plans was even less.*

*FACS in Kind support dwindle and ceased* [with transfer to NGOs]*"*.

Association member working with NGO provider (group home)

Current reviews have equally been marred by inconsistency in approach.

*"The planners at the first full review* [this year] *were experienced and knowledgeable.* [However] *there is no consistency with the Planners in how they assess a person needs.*

[The facility] *had prepared portfolios, which contained the assessments and evidence needed for each person, but the outcomes were very different. One Planner allows Dietetics to be included in the plan, another Planner stated that it was not allowed.*

*Each Planner had a preferred allied service, which they would include if possible. One planner advocated for an exercise physiologist.*

*During the planning meetings, we had to prioritise assistive technology items as NDIS would not fund all the equipment a participant required* [despite multiple needs being assessed as being required by Occupational Therapists and Physiotherapists].*"*

Association member working with NGO provider (group home)

*"Insufficient funds allocated to NDIS Co-ordination. Benchmark too low.*

*The NDIA planners fail to take into account the number of hours it takes to:*
*# liaise with families and services; # provide support to family members;*
*# Develop agreements: # check that there is sufficient funds in the plan;*
*# liaise with providers to adjust quotes and plans; # find service providers;*
*# access the NDIA portal* [even the coordinators have difficulty accessing the portal]; *# provide reports; # attend meetings; # submit reviews of plans."*

Association member working with NGO provider (group home)

*"The new NDIS plans are not responsive to sudden changes in circumstance. If the person has funding identified in the correct support area of their plan, then a referral can be raised and the service provided.*

[But] *if there is no funding then the Coordinator has to go back to the NDIA to review the plan. Unknown period as to when the plan will be reviewed and if the extra funds will be approved. Meanwhile the client is disadvantaged.*

*Several clients did not have sufficient funds in their plans for a new wheelchair. For a period of more than 6 months, these people were unable to attend the day placement, despite having the funding …"*

Association member working with NGO provider (group home)

Issues have also arisen with the use of the NDIA portal.

*"Need to set up a government account for each person.* [However] *many of the persons responsible are elderly and have little, if any IT experience.*

*The portal is difficult to access and is not user friendly.*

*The NDIA IT Communication email system is not compatible with NGO IT Systems.*

[At my facility] *the Coordinators have to contact the Nurse Coordinator as they cannot access the emails."*

Association member working with NGO provider (group home)

## (c) the accessibility of early intervention supports for children

The Association in recent years has raised concerns with the rising complexity of healthcare needs required by students with disabilities in NSW schools, particularly as it is reasonably anticipated that an increased participation of students with more complex needs under the NDIS would indeed occur.

Whilst the Association has been a party to earlier discussions regarding the role and boundaries in the provision of support at school for students requiring health care procedures, this was primarily directed to support students with non-complex needs. The NDIS has however the capacity, as it should, to result in many more students having access to resources to support their attendance at school. It is realistic to conclude that the Department of Education ('DET'), or other educational providers, will be supporting more students with much more complex needs into the future.

On this basis, the Association has made representations to DET regarding the establishment of healthcare coordinator roles filled by specialist disability nurses to attend to this growing cohort of students in NSW schools and provide support and/or oversight to those existing school officers providing support to students with less complex needs. The Association holds the view that depending on the level of demand, these specialist nurses could provide oversight and support to a cluster of schools or there may be particular schools that would benefit from the full time presence of a qualified nurse to coordinate the complex healthcare needs of a group of students. These would enhance and aid school participation of children with disability.

The establishment of the NDIS is a very welcome and overdue reform but possible benefits for school age children with disabilities will continue to be stymied without a proper framework of support and clinical care/oversight. It is essential that the growing complexity of needs among students with disabilities is accompanied by a renewed approach to their health needs to ensure that the complex interface between their educational/disability/health needs is responded to effectively.

This is especially the case when considering Australian Institute of Health and Welfare data that highlights the very significant gap in health outcomes between Australians with disability and those without[5]. In order to close this gap, all institutions engaged in supporting people with disabilities must ensure that adequate measures and skilled personnel are in place to ensure a holistic response to the needs of people with disabilities.

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[5] *Health status and risk factors of Australians with disability 2007–08 and 2011–12*, **Australian Institute of Health and Welfare**, 25 February 2016 (see below link) http://www.aihw.gov.au/publication-detail/?id=60129554512

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

It may do well to briefly summarise the approach adopted by the NSW Government to this privatisation, which is characterised by a *complete withdrawal by the government from the provision of disability services* and the *forced transfer of employment of its staff*.

The NSW Government on 6 December 2012 entered into a *"Heads of Agreement between the Commonwealth and NSW Governments on the National Disability Insurance Scheme"* ('HoA 2012'). This HoA 2012 established the overarching agreement and framework to facilitate the 'roll out' of the National Disability Insurance Scheme ('NDIS') within NSW.

Section 33 of the HoA 2012 stated that *"Following commencement of the full NDIS, **the NSW Government will not provide** any residual specialist disability services or basic community care services."* [emphasis added]

The effect of this approach was that the NSW Government (via the Department of Family and Community Services) would vacate its existing and longstanding provision of various services within this area (including home care, supported living, respite and residential services) and transfer these in their entirety to the NGO sector. By vacating the field to the NGO sector arising from the roll out of the NDIS, the NSW Government would as a consequence cease to require or employ persons currently providing such FACS services at the time of transfer to the NGO sector.

This has and will continue to affect the employment of several hundred staff members employed in nursing classifications by FACS.

The approach to vacate the disability field by the NSW Government became further crystallised when the NSW Parliament passed the *National Disability Insurance Scheme (NSW Enabling) Act 2013* ('Enabling Act').

The Enabling Act, whilst setting out certain protections for FACS employees transferring to NGO providers arising from the roll out of the NDIS, enabled the Minister for Disability Services to *unilaterally transfer* FACS employees to the employment of a NGO provider.

This power is enlivened by sub sections (2) and (3) of Section 14 in the Enabling Act:

> *"(2) The Minister may by order in writing transfer the employment of a disability services employee* [FACS employee] *to the employment of the new employer to give effect to a transfer agreement.*
>
> *(3) A transfer of employment under this section **does not require the consent** of the person transferred."* [emphasis added]

This was and remains an extraordinary approach and essentially reduced these valuable FACS staff members to be something akin to any other possession or asset to be exchanged or sold during this process. It was *industrial conscription* of the most egregious kind, and one that has caused considerable distress and harm to a number of such employees.

This has only compounded what is, in the view and experience of the Association, one of the largest and most complex privatisations involving the transfer of services and employment from the government to the private sector due to the sheer scale and/or complexity of the services, assets and employees to be transferred; and that these would be unilaterally transferred to a multiplicity of NGO providers/employers spread throughout the state.

Further, all the new providers of such services, and therefore the employers of transferred FACS staff, will operate within the federal industrial relations jurisdiction. Transferred staff, their industrial representatives, and in turn providers are required to negotiate and make good the interface between commitments made by the NSW Government to such staff and the *Fair Work Act 2009* and ancillary legislation. Certainly there is no dispute between the Association and FACS that the NSW Award applicable to nurses working in FACS, the *Nurses' (Department of Family and Community Services - Ageing, Disability and Home Care) (State) Award* ('NSW Award') follows such employees to their new NGO sector employer as a copied State instrument - as per Part 6-3A of the *Fair Work Act 2009*.

In addition to the employment conditions set out in the NSW Award, the Minister for Disability Services has, as permitted under the Enabling Act, entered into additional commitments or guarantees on behalf of FACS employees with the NGO providers (a transfer agreement[6]). These include a two year employment guarantee period (if a permanent employee at the time of the transfer); maintenance of existing conditions during that period; and an undertaking that the NGO provider cannot initiate the making of a federal enterprise agreement to cover transferred FACS staff for a period of two years.

Despite these additional commitments being welcome (over and above those that may have accrued from the copied State instrument), the Association and affected members have not been able to access the employment guarantees entered into between the Minister and NGO providers - effectively on their behalf. Certainly the components of what is said to be guaranteed have been identified, as have certain extracts, but not the guarantee itself. Accordingly, transferred FACS staff have not been able to access how the Minister has articulated these requirements and in what manner the NGO provider is required to demonstrate such a commitment - or indeed what penalty may be applied if compliance was not forthcoming.

Another area of deep concern for transferred staff is that beyond the guarantees that may be in place for the first two years post transition to the NGO provider, their position and conditions of employment may well become more precarious or change.

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[6] Section 14, *National Disability Insurance Scheme (NSW Enabling) Act 2013*

*“Talk around the place is that after the two years end, the nursing model carried over from FACS will be changed.”*

Association member working with NGO provider (group home)

A concern exists that models of care developed and deemed as being necessary by FACS prior to transfer will not be maintained - or at the very least pressure will arise to modify staffing profiles to constrain labour costs. This should not be the basis of determining the level of care and support required/provided. (See additional comments included in ToR (f)).

Based on feedback from members, privatisation of services and the lack of regulation with this system has exposed situations where individuals have been charged large amounts for services which has left them with inadequate funding for other services. Without government services those individuals with complex and high risk behaviours that private providers will not accept have no safety net if government services are completely withdrawn. The privatisation of disability services within NSW has led to the loss of best practice disability models along with staff with expertise and knowledge. This has severely impacted the quality and level of care provided. Privatisation does not provide a public safety net for disability services for people with disabilities that are beyond the private sector. It creates a business model of care, with the most costly or clinically onerous clients excluded.

May, Forrester, Webber, Roberts, Spreckley, Scheinberg and Williams state:

“*… there are some downsides to market forces operating within a publicly funded framework. For example, there have been reports of organisations with little experience in key areas of disability care winning tender processes. There may also be economic incentives to provide centre-based care, which minimises the cost of travel time for professionals, rather than care as currently provided. Market forces have also lead to closure or acquisition by larger providers of small long established services.*

*Service outlined in individual support plans have not always been available. In some instances there is an insufficient supply of suitably trained professionals, particularly in rural and remote areas”.* [7]

It is recommended that sufficient attention must be given to promoting equity of outcomes among individuals with diverse needs and circumstances. Staff with sufficient training and knowledge need to be used when developing, implementing and reviewing plans to ensure collaboration with individuals, carers and their families under the NDIS. In our view a regulatory system must be put in place and government services must provide a safety net for those complex care needs to be met.

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[7] *“Current status opportunities, challenges and the paediatrician’s role as the national disability insurance scheme rolls out across Australia”*, May, T, Forrester, M, Webber, M, Roberts, J, Spreckley, M, Scheinberg A, and Williams K, 2018, **Journal of Paediatrics and Child Health, 54**, pp, 8.

## (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

Feedback from some members to the Association identify concerning aspects and trends in relation to services (or lack thereof) being provided to people with disability. Alternatively, services may well be engaged to be provided but do not, for example, fall within the provision of their intended effect ie meaningful community participation.

> *"I have witnessed one client being picked up by a provider and is seated in the vehicle until a client in another house is picked up forty five minutes later … during the near hour wait the client is seated in the vehicle and the provider is playing on a mobile device. This occurs regularly …"*
>
> Association member working with NGO provider (group home)

> Our group homes *"…have agreed times to pick up a client (with challenging behaviour) … they* [provider] *don't turn up at the agreed times. This places staff caring for this resident at risk of physical and verbal aggressive outbursts.*
>
> *This turning up late happens on a regular basis, at times they don't turn up at all. On many of the occasions of not arriving they do not notify the unit to allow appropriate support to be provided to the client."*
>
> Association member working with NGO provider (group home)

> *"We have had one resident who refused to go out with a provider stating that he is sick of going out and shopping at girl's shops."*
>
> Association member working with NGO provider (group home)

> *"… scheduled to have three outings each week of one hour duration. They go out for 15 - 20 minutes … taken to close by McDonalds and has something to eat and drink then is returned to the house. Provider is paid for the hour. The meal time management plan for this resident states they are on a minced and moist diet … which does not include burgers, nuggets, chips …"*
>
> Association member working with NGO provider (group home)

*“Providers are supplied with the Meal Time Management plan identifying what the client can eat and drink. Thickener is supplied by the group home for those who require these items or pre-thickened drinks … very few ask or use these items. The Meal Time Management plans identify if the clients have a medical condition which prohibits some foods from their diet. We have instances where this is disregarded or perhaps just not understood by the staff member of the provider.*

*We certainly have had episodes of such requirements being regularly overlooked.”*

Association member working with NGO provider (group home)

Older *“… resident who went out with a provider suffered what was described as a turn was returned back to the group home instead of calling an ambulance and going to hospital. It is only a matter of time before a serious incident.”*

Association member working with NGO provider (group home)

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

Arising from dispute proceedings initiated by the Association before the Industrial Relations Commission of NSW (‘IRC of NSW’) in 2017, a service continuity obligation was confirmed as being imposed by FACS/the Minister upon any new NGO provider. This reflected commitments provided to the IRC of NSW by FACS in conciliation conferences during Matter No 2017/00240154.

The necessity of this service continuity obligation arose from concerns held by our members that the model of care utilised by FACS may not be retained or continued by NGOs post transition ie the level of care determined and provided by FACS based on the care plan of residents immediately prior to the date of transition may not be maintained or become degraded in the period following transition. In other words, a group home that may have had a nursing model of care identified and used by FACS due to the clinical care needs of residents may have been subject to alteration or the level of clinical care diminished post transition by NGOs.

In response to such concerns, and the agitation of the Association regarding this issue during the above dispute, FACS issued a schedule dated 23 August 2017 that in particular set out the following:

*“**Clause 7.23***

*7.23 The Purchaser must and must ensure that each Granting Party (and the Granting Party must)(to the extent such matter is in the direct control or influence of the Purchaser and/or the Granting Party):*

*(a) in respect of accommodation and respite Participants:*

(i) *the Company continues to provide disability services to each Participant in a manner that is reasonably consistent with such provision in the twelve (12) months prior to Completion, unless the Participant makes an alternative choice, and subject to funding from funding arrangements, for a period of at least two (2) years from Completion;”*

Whilst this at least attempts to create an obligation on NGOs to provide continuity of models of care for an initial period of two years, the enforcement of such an obligation is at the discretion of FACS. For example, in a recent situation, the Association raised with FACS concerns that members at a particular facility were experiencing some difficulties arising from what they believed was a clear variation to the model of care (and staffing profile) transferred from FACS originally. When FACS subsequently responded to such concerns, it essentially just confirmed to the Association that it was satisfied that the particular NGO was compliant with its obligations.

Regardless of any remaining concerns the Association and its members have in this example, or any future difficulties with other NGOs, there is little to no jurisdiction available to the Association to test or enforce such a contractual commitment between FACS and the particular NGO.

When added to some of the examples demonstrated elsewhere in this submission, the progressive transition of services from FACS to NGOs (understood to have been some 40% of the disability and accommodation services provided in this state), this requires heightened accountability and transparency, underpinned by a clear, independent regulatory system.

Aspects of the transfer of FACS services, assets and staff to NGOs, along with commitments made about care or employment arrangements, are not suitable or likely to be able to be dealt with by federal organisations established to oversight the NDIS, such as the NDIS Quality and Safeguards Commission.

How oversight is carried out in general and compliance specifically achieved within the NDIS was a consistent theme of a considerable amount of feedback received. It may reflect a lack of information or knowledge or access but in any event, something needs to change.

“[The NGO operator] … *seem to have been given a poor handover from FACS. No point of contact for querying various issues except ex FACS managers who are often ill informed through no fault of their own.*

*No oversight from any Government body including FACS that I can see, client case managements not being maintained …”*

Association member working with NGO provider (group home)

*“Money for groceries/food for residents in care,-senior staff use debit cards (often in their names) to draw from client/resident money to go out shopping for food.”*

Association member working with NGO provider (group home)

*“Nonsensical outcomes. For example, one resident needs a commode but has to be in their name under NDIS. Therefore not for co residents to use that person’s personal commode … so other residents in need of commode have to be funded for their own chair. The group home has five residents therefore for each resident to use a commode would result in five commodes cluttering up a shared bathroom.”*

Association member working with NGO provider (group home)

*"Offsite day placements charging up to $27,000 per resident per year for a service that our accommodation staff used to provide at no extra cost via onsite activities and community access.*

*Staff even have to provide transport and arrange extra food money for these day placements.*

*Care in these day placements seems to be less than satisfactory … as residents sometimes have returned to the group home in a poor state or with unsettled behaviour."*

Association member working with NGO provider (group home)

*"At present these clients are being financially disadvantaged by NGOs providing services already provided by their present staff and carers, these are being charged to the clients until they no longer are financially able to pay and it then stops, creating further disturbance in the clients life's."*

Association member working with NGO provider (group home)

*"Requests for review of plans and assistive technology reports were submitted as required to NDIS so our clients could be funded for service and especially equipment they required. Reviews fell in a black hole … could not contact NDIS directly only communication channel was to a generic call centre in Canberra."*

Association member working with NGO provider (group home)

*"… client disadvantaged as they could not attend Day programs or community based activities, as they did not have the equipment to do so. NDIS was funding a day program service that the participant could not utilise."*

Association member working with NGO provider (group home)

*"Participants need to pay from their pension for incontinent aides, thickeners and repairs to their mobility aides."*

Association member working with NGO provider (group home)

*"The fees charged by* [Service Providers] *are excessive. We have been using one which is charging $180.00 plus per hour. Due to the excessive cost of the* [service], *there is insufficient money allocated in the plans."*

Association member working with NGO provider (group home)

*"As NDIS had approved supported independent living funding submitted by* [the facility] … *it left a gap in the funding available to these participants for core supports such as community based programs.*

*For example,* [the facility] *was approved for 24 hours supported independent living funding for one participant. Therefore no funding available now to the participant for day programs. This has effected a lot of our clients."*

Association member working with NGO provider (group home)

*"Overall my impression is that the NDIS and privatisation via NGOs will result in a monumental waste in tax payers' money … ironically with lesser positive outcomes for the disabled in accommodation care settings."*

Association member working with NGO provider (group home)

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

As noted throughout this submission, a concern exists that models of care developed as being necessary by FACS prior to transfer will not be maintained - or at the very least pressure will arise to modify staffing profiles to constrain labour costs - at the completion of the initial two year period (or earlier).

Some of the key questions continually asked by nursing members working in FACS (and slated for transfer to a NGO) over the last three to four years have included:

*"What happens after the two years?"*

*"Will I have a job after that?"*

*"Can you guarantee that my conditions of employment won't be cut after two years?"*

The response from FACS has largely been that this is a growth industry, experienced disability nurses will be in short supply, and effectively supply and demand will serve to protect the employee's interests, along with the needs of people with disability. These responses have provided little comfort or assurance.

It is perhaps one thing, after weighing up the facts, to willingly make a decision about one's employment, acknowledging that it may have an element of risk but nonetheless to *back yourself in*. It is quite another to have that uncertainty and potential loss and dislocation *thrust upon you without your consent* - as the Enabling Act does.

Surely this requires a heightened level of vigilance and has the real potential to create considerable workforce dislocation in the years ahead.

> *"Ex FACS employees on 2 year FACS conditions till expiry … zero communication on conditions after* [that date] *… eg pay rate and long service leave pay rates to provide assurances to staff for their future. I currently have sent requests for information with no response …"*
>
> Association member working with NGO provider (group home)

Some of this has already been demonstrated or hinted at with casual FACS employees who were transferred to a NGO. Regardless of the two year employment guarantee provided to permanent employees, casual and temporary employees were only provided an employment guarantee of six months. For casuals, the practical application of this was that *"… you will be retained on the new operator's casual roster for at least the six month Employment Guarantee period"*.[8]

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[8] As contained in various updates to FACS staff, and included in the *"Employee Information Kit"* made available to transferring staff, dated August 2017, pp 7.

So what approach has been adopted to casual staff as the six month period is due to expire? Unfortunately based on some member experiences, the mooted approach by some NGOs is to *quietly suggest* to such transferred staff that they will not remain on the casual roster beyond the six months, although that may be negated if they were to resign (and effectively jettison their copied State instrument) and are re-employed on the federal Nurses Award[9] (a by far inferior industrial instrument).

Settings aside the legalities of such an approach, and that challenging it may lead to a Pyrrhic victory for the employee, it reflects the mindset of some NGOs that the quicker they disentangle transferred staff from any FACS imposed commitments or obligations imposed by the *Fair Work Act* for such staff, the better.

This can only be described as an approach based on cost and not need or any desire to retain experienced staff who have particular relationships with residents for example in a group home. The loss of nursing staff due to such an approach, who have a long established rapport and experience with residents is not unexpectedly distressing for people with disability and their carers/families.

Attracting and retaining staff has not surprisingly been difficult.

> *"Poor recruitment adverts say nothing in terms of location, pay and what is involved in job.*
>
> *No response from Email only address when I have sent queries on job ads.*
>
> *New recruits either leaving on their first shift or never turning up."*
>
> Association member working with NGO provider (group home)

> *"Poor recruitment and lack of assurances causing chronic staffing problems eg people using up lots of their sick leave and recreation leave. This is negatively impacting the ongoing care of our disabled residents, some of who have medical issues.* [The NGO] *don't like Agency staff but they are a mainstay - otherwise constant overtime."*
>
> Association member working with NGO provider (group home)

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[9] Nurses Award 2010 [MA000034]. This award, one of the so-called Modern Awards established by the Fair Work Commission, can only be described as the most basic of safety nets, with far inferior rates of pay, for example, to that of the copied State instrument available to transferred FACS employees.

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

Variously touched upon in other ToR.

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

It is for these very concerns that the Association and members have continually called for the NSW Government to reverse its decision to abandon state disability services. As noted throughout this submission, there are some vulnerable people with disability with complex co-morbidities whose needs will not be compatible with the approach of the NDIS and NSW Government.

The Association is made aware of incidents by members of people with disabilities being admitted into acute hospitals and mental health facilities, and remaining in those facilities well beyond the original episode of care has concluded - as they are difficult to place and/or the previous group home is refusing to accommodate the resident again due to concerns that they cannot adequately manage them.

For example, a person with disability was admitted to a Sydney metropolitan hospital for some three months as a placement in a group home proved difficult. During that time the person was violent and was eventually found a placement - but only after pressure from the hospital nursing staff who were subject to constant attacks.

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

The Association continues to discuss with members as to what mechanisms may be utilised to improve the provision of services.

## (k) any other related matter

It is understood by the Association and its members that persons with disability who were over 65 years of age were not entitled to NDIS funds. However they were guaranteed continuity of service (‘COS’) using specific COS funds. However, per members, this has not proved to be readily available.

> *“Prior to transfer FACS provided funds for essentials such as incontinence aids, Dietetics. Since transfer to a NGO, funds have not been available.*
>
> *Whilst COS exists it has been impossible to receive funds.* [The facility] *has been paying in the short term, but this will not continue and no-one is able to provide information how to access funds.”*
>
> Association member working with NGO provider (group home)

# ANNEXURE A

## The Impact on Government Run Disability Services

As current and long-time employees of Stockton Centre, the impact on staff, clients and families is ongoing due to the fact that the three centres at Stockton, Tomaree and Kanangra are still operating.

These centres have been under closure threats for over 40 years at least, under successive NSW Governments at the detriment of all involved.

The stress and anger felt each time by the staff at Stockton has had a negative impact on staff retention and employing new staff only to have the State Government change it decision to maintain services through FACs for two more years at this stage. Unfortunately, most of the indirect support has been offered redundancy or relocation to other positions. The kitchen, laundry services and our main stores have been closed resulting in the out sourcing of these services, which now is difficult to understand due to the extension of the Stockton, Tomaree and Kanangra for two more years at this time.

The decision of the State Government to close Disability Services i.e. Aging Disability and Home Care has occurred even though there are three sites still in operation and will be for a further two years at this time.

The State Government informed everyone that all services will be run under the NDIS through NGOs by June 2018 but we are still operating under a State Government Department. The staff, clients and families have been left in limbo on what is happening and no real information on when these new houses will be started. There is still no clear information on which will be Medical and Non-Medical group homes in the region. This has caused staff to either leave the service all together as they felt there is no future in Disability and as 30 June 2018 loomed closer. Recruitment has been happening on a regular basis with new staff coming on board but not keeping up with those leaving the service. Due to this happening, workloads have increased for remaining staff working at these sites who are regularly working short and creating concerns with decreased skills level.

We no longer have access to a canteen to purchase food and take clients to support and encourage independence. We had an onsite shop (Hand-mart) which provided clients the opportunity to purchase items as part of their ongoing education to be independent prior to going to the group homes. Clients/staff now use a vending machine to purchase drinks and confectionary - hardly a healthy alternative.

Stockton has had a non-admission policy for many years except when the Minister deemed it necessary to support people in the community who were in crisis and needed the expertise of the Nursing staff at Stockton.

The closure of this service and others will leave the State Government and other services with no support and many people with a disability or dual diagnosis will be placed in services that are suffering from staffing and bed shortages, and without the expertise to support these people in crisis.

Hopefully this inquiry will review the NSW Government's decision to withdraw totally from providing at the very least a service of last resort. This is needed to ensure quality and consistency of support to the NGOs and other agencies to ensure that people with a disability are provided the best possible outcome so clients can live a full and rewarding life in the community. Public operated services can very effectively complement NGOs and work collaboratively.

We invite the inquiry to visit these three facilities to talk to the staff, families and clients to hear our stories.

Thanking you in anticipation of reviewing our concerns for all involved.

*NSWNMA Stockton Centre Branch President*

*NSWNMA Stockton Branch Secretary*