

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

Organisation: Benevolent Society

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

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1. Introduction

The Benevolent Society welcomes the opportunity to contribute to the *Inquiry into the National Disability Insurance Scheme (NDIS) and the provision of disability services in New South Wales* (NSW). As the organisation which took over the clinical and case management disability services across NSW which were previously provided through the Department of Family and Community Services' (FACS) Ageing, Disability and Homecare (ADHC) group and welcomed former FACS employees into our organisation just over a year ago, we are well placed to comment on the transition to the NDIS and on some aspects of the transfer of disability services to the non-government sector in NSW.

Whilst we recognise that inquiries such as this are political in nature, The Benevolent Society is nevertheless sharing our experience in good faith to ensure that we are open about the challenges under the new scheme that clients, service providers and disability sector workers are experiencing.

The Benevolent Society strongly supports the NDIS and views it as a vital reform to help people with disability to live their best lives. We accept that there will be challenges in rolling out a scheme as transformative as the NDIS. The Benevolent Society wants to engage in frank discussions and work constructively with state and federal government and other stakeholders to make sure that the scheme is a success for the 140,000 people with disability across NSW who are expected to access the scheme.

2. About The Benevolent Society

The Benevolent Society is Australia's first charity. We're a not-for-profit and non-religious organisation and we've helped individuals, families and communities achieve positive change for over 200 years.

Since our earliest days, we've been driven by a vision of a just society where all Australians live their best lives. We support people across the lifespan, delivering services for children and families, older people, women, people with mental illness, people with disability and through community development programs.

Following the acquisition of disability support services from the NSW Government in 2017, we now have over 550 new staff providing disability services across New South Wales to approximately 2,000 clients. The Benevolent Society is now one of the largest providers of specialist clinical disability services in Australia.

Snapshot

- The Benevolent Society is a secular non-profit organisation with 1,615 staff and 658 volunteers who, in 2016/17 worked with 54,038 clients.
- We deliver services from over 60 locations with support from local, state and federal governments, businesses, community partners, trusts and foundations.
- Our revenue in 2016/17 was \$108.5 million.
- In 2016/17, 89 per cent of our income came from government sources.
- The Benevolent Society is a company limited by guarantee with an independent board.

3. Key Messages and Recommendations

The Benevolent Society recognises that the primary responsibility for the NDIS sits with the National Disability Insurance Agency (NDIA) which is a Commonwealth Government body. For the purposes of this inquiry we call upon the NSW Government to use its position on the Council of Australian Governments (COAG) Disability Reform Council (as represented by the NSW Minister for Disability Services and the NSW Treasurer or their delegates) to communicate with, and influence, the policies and practices of the NDIA.

3.1 Implementation of the NDIS and choice and control for people with disability

Evidence suggests that the NDIS is improving the lives of many participants, who report more choice and control over the supports that they receive. However, not all participants are benefitting from the scheme.

3.1.1 Planning and advocacy

The planning process and the quality of NDIS plans is a major factor in a person's experience under the NDIS.

The Benevolent Society recommends that:

1. The NSW Government engages with the NDIA to improve the NDIS planning process by:
 - (a) increasing the number of planners so participants can get face-to-face planning meetings in a timely way;
 - (b) ensuring the NDIA attracts and recruits people with understanding of, and experience with, people with disability to become NDIS planners to improve the planning process, and provides adequate training and supervision for planners; and
 - (c) requiring the NDIA's planners provide an explanation of why the recommendations of experienced clinicians are not included in a participant's plan.
2. The NSW Government continues to fund disability advocacy until it can demonstrate that these services are being fully funded to the same extent by the NDIS.

3.1.2 Communication

The Benevolent Society finds communicating with the NDIA difficult as it is sometimes hard to get through to the NDIA by phone; advice provided by the NDIA can differ depending on who is providing it; and information provided by the NDIA is not always in a format which is accessible to people with disability.

The Benevolent Society recommends that:

3. The NSW Government requests that:
 - (a) the NDIA lifts the cap on the number of staff employed by the NDIA to improve the responsiveness of the NDIA to queries from clients and service providers;
 - (b) the NDIA appoints case managers or primary contact points for each participant so that participants and service providers can get consistent advice in relation to the participant's plan; and
 - (c) the NDIA uses a range of different channels and formats that are more accessible for people with disability to communicate key information on the scheme to NDIS participants and potential participants.

3.1.3 Interface with state based systems

Since the introduction of the scheme, there has been ongoing tension between the NDIA and state health systems over what types of services are included under the NDIS and what issues remain the responsibility of the state health system. For example, it remains unclear if treatment for difficulty swallowing (or dysphagia) for people with disability is covered by the NDIS or not.

The Benevolent Society recommends that:

4. The NSW Department of Health and the NDIA clarify the status of the treatment of dysphagia for people with disability within the NDIS and the state health system.

3.1.4 Access for people with psychosocial disabilities

People with psychosocial disability are having disproportionate trouble accessing the NDIS for a range of reasons including: meeting the eligibility criteria given the nature of their disability; and the knowledge about the NDIS amongst GPs and specialists.

The Benevolent Society recommends that:

5. The NSW Department of Health undertake an education campaign to improve doctors' knowledge of the NDIS, and particularly of eligibility requirements under the NDIS for people with psychosocial disabilities.
6. The NSW Department of Health guarantee continuity of supports for people with psychosocial disability who are not eligible for the NDIS.

3.2 Experience of people with complex care and support needs under the NDIS

The requirements of people with complex support needs are not always being met under the NDIS.

The Benevolent Society recommends that:

7. The NSW Government encourage the NDIA to finalise and release the pathway for participants with complex support needs and the policy on 'provider of last resort'.
8. The NSW Government requests that the NDIA include funding for specialist support coordination in the NDIS plans of participants with complex support needs.
9. The NSW Government request that the NDIA ensure that plans for people with complex support needs include flexible, contingency funds to be used at times of placement breakdown or crisis, or to adapt to changing circumstances for NDIS participants.
10. The NSW Government embed the Integrated Service Response Project into the system long-term to assist with coordination of NDIS participants with complex support needs.

3.3 The effectiveness and impact of privatising government disability services

A number of gaps in the disability service sector have arisen as a result of the transfer of disability services from the government to the non-government sector. A particular gap which concerns The Benevolent Society relates to voluntarily relinquishment of children with disability and the NSW child protection system.

The Benevolent Society recommends that:

11. The NSW Government improve the interface between NSW child protection systems and the NDIS to ensure that children with high support needs have their rights to stable and secure accommodation, consistent support services and meaningful relationships with their families met.

3.4 Accommodation services under the NDIS

The NSW and Commonwealth Governments need to look closely at the issue of accommodation for people with disability because the system under the NDIS is not working, particularly for people with complex support needs.

The Benevolent Society recommends that:

12. The NSW Government introduce incentives for developers to build housing which can be used as group homes for people with disability.
13. The NSW Government request that the NDIA review its approach to Specialist Disability Accommodation funding to extend it to cover accommodation modifications for people with complex support needs.

3.5 Workforce issues impacting the delivery of disability services

It is well documented that the disability workforce will need to grow to support the NDIS. However, experienced staff are choosing to leave the sector rather than operate in the NDIS environment. Coordination of the placement of students in the disability sector has also decreased following the transition of disability services from the government to the non-government sector.

The Benevolent Society recommends that:

14. the NSW Government and/or Commonwealth Government establish a Workforce Development Fund to provide grants and other financial incentives to encourage service providers to take on students in order to build the disability sector workforce.
15. The Workforce Development Fund should also include funding for organisations to support the professional development of staff.
16. The NSW Government request that the NDIA should develop guidelines to outline clear, reasonable and sufficient supervision requirements for students in the disability sector.

3.6 Financial sustainability of service providers

The Benevolent Society, like many service providers, is finding that adjusting to the NDIS market system is difficult. Operating under the NDIS model is placing pressure on the financial sustainability of service providers. Administration and difficulties with the NDIS systems, such as the portal, contribute to these issues. In some cases, the prices charged for services and travel under the NDIS are insufficient to cover operating costs.

The Benevolent Society recommends that:

17. The NSW Government request that the NDIA resolve issues with the NDIS portal and the inability of service providers to bill for services delivered to a client prior to a plan review. This should include the development of a notification system for clients and service providers alerting them when a plan review process is underway.

18. The NSW Government request that the NDIA provides accessible information to participants and the public about the providers available in the market and indicators of participant satisfaction with those providers.
19. The NSW Government request that the NDIA review travel costs under the NDIS, with consideration of the impacts on service providers' ability to provide services under the NDIS in rural and remote areas of NSW.
20. Travel costs include funding to cover outreach from specialists where services are not available in an area, to increase choice and outcomes for participants, and to minimise harm from a lack of tailored services available.

3.7 Other matters

There is no funding in the system for research and practice improvement.

21. The Benevolent Society recommends that the NSW and/or the Commonwealth Government commit funding for research and innovation in the disability service sector.

4. Response to the Terms of Reference

Given the scope and scale of the NDIS, it is not surprising that there is, and should be, scrutiny of its implementation. The challenges of the scheme have been well-documented through a number of high profile recent reports from the Productivity Commission and Federal Parliament's Joint Standing Committee on the NDIS.¹ These reports include a number of recommendations for Federal, State and Territory Governments and for the NDIA on how to address the issues emerging from the NDIS trial-sites and roll-out so far.

The NDIA has responded to these reports and recommendations in part by introducing, or promising to introduce, a number of different pathways to improve the NDIS for participants and a review of NDIS prices. As the Terms of Reference for this inquiry cover many of the issues which have already been discussed in detail in the previous reports and inquiries mentioned, we recommend that the Committee takes note of their findings and recommendations as they remain relevant to the current inquiry.

4.2 The implementation of the NDIS and its success or otherwise in providing choice and control for people with disability;

4.2.1 Overview

Whilst there are many aspects of the implementation of the NDIS which our staff find frustrating, we do not want to distract the inquiry with a laundry-list of all of the administrative and technical problems with the scheme which are most appropriately raised with the NDIA. However, we will provide a snapshot of some of the major challenges that our organisation and our clients face to

¹ Including the Joint Standing Committee of the NDIS' *Progress Report* in September 2017, the Productivity Commission report on *NDIS Costs* released in October 2017, and the Joint Standing Committee on the NDIS' *Transitional Arrangements for the NDIS* report released in February 2018.

provide context to consider whether the NDIS is meeting its stated goal of providing greater choice and control for people with disability.

The consumer-directed NDIS system is based on the premise that exercising choice and control will deliver the best outcome for people with disability, but choice and control is only effective if individuals are able to exercise that choice and control meaningfully. The capacity of people with disability to identify and access the services that best meet their needs is varied, and the support provided under the scheme to help participants is mixed.

Given that there were 183,965 Australians being supported by the NDIS as at 30 June 2018, and the scheme is predicted to include 460,00 participants when fully implemented,² it is to be expected that there will be a spectrum of participant readiness to navigate the scheme. The fact that trial participants were lower than expected when compared to bilateral estimates and only 69 per cent of the 2017-18 bilateral estimate was reached³ suggests that some people are having trouble navigating the system. That is certainly consistent with our experience.

We have found that for many people the NDIS is serving them well. For people with 'straight-forward' disability support needs, mainly related to physical disabilities, who are able to communicate their needs clearly and get a suitable package, the NDIS is meeting its objective overall. The NDIA states that:

- 91 per cent of parents or carers of children aged between 0 and six have reported that the NDIS has helped with their child's development; and
- 71 per cent of participants aged 25 and over have reported that the NDIS had helped them with daily living activities.⁴

However, only 67 per cent of participants aged 25 and over have indicated that the NDIS has helped them with choice and control.⁵ The NDIS is proving difficult for some cohorts of participants and potential participants to navigate which means that they may not be able to reap the benefits of exercising greater choice and control over the services and support available to them.

These cohorts include: people with complex support needs; people with psychosocial disability; people in remote and regional areas; people with cognitive impairment or parents/carers with cognitive impairment; Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse (CALD) backgrounds.

Some of the aspects of the implementation of the NDIS which are limiting participants' ability to exercise choice and control are outlined below.

4.2.2 The planning process

a) Issues with the planning process

The planning process has been a major impediment to full access and participation in the NDIS. Problems with the planning process have been well documented and include:

- many planners do not have experience with, or understanding of disability;
- not all planning processes have been conducted face-to-face, with some plans being discussed over the phone or without a carer or support person present;
- many plans do not allocate enough services and supports for clients, and expert input from experienced clinicians about service and support needs is not being reflected in plans;

² National Disability Insurance Scheme, COAG Disability Reform Council, *Quarterly Report*, 30 June 2018, at <https://www.ndis.gov.au/medias/documents/coag-report-q4-y5-full/2018-Q4-June-COAG-report-Full.pdf>

³ Productivity Commission (2017), *National Disability Insurance Scheme (NDIS) Costs*. Study Report, Canberra.

⁴ NDIS (2018), <https://www.ndis.gov.au/medias/documents/coag-report-q4-y5-full/2018-Q4-June-COAG-report-Full.pdf>

⁵ NDIS (2018), <https://www.ndis.gov.au/medias/documents/coag-report-q4-y5-full/2018-Q4-June-COAG-report-Full.pdf>

- inconsistency of plans between people with similar needs; that is, people with less severe needs getting more service and support funding than those with more complex needs;
- long timeframes for getting plans approved and for getting basic, but fundamentally necessary, equipment approved in plans; and
- an opaque and time consuming plan review process. In many instances participants are not informed a plan is being reviewed. When plans are being reviewed, which can be a lengthy process, service providers are not informed and all service bookings for that participant will be removed from the system. This means that services that have been provided cannot be billed.

Case study: Inconsistent and inadequate support coordination

*The Benevolent Society's client Jane*⁶ has a plan which includes \$7,000 for support coordination and only \$4,000 for services to assist 'improved daily living', which is where she needs the most support. In comparison, another client Barry, uses a wheel-chair and has severe mental health issues and will need significant support to coordinate his services needs and implement his plan. Barry's plan includes \$90,000 for services but only \$1,000 for support coordination.*

The Federal Government's Joint Standing Committee on the NDIS recognises that

the quality of NDIS Plans appears to be dependent on two main factors 1) the NDIS Planner's knowledge and expertise; and 2) the level of advocacy families and NDIS Participants can undertake and their knowledge of the disability sector.⁷

The Productivity Commission recommended that the NDIA ensure that planners have a general understanding about different types of disability and specialist planning for types of disability that require specialist knowledge, such as psychosocial disability. The Benevolent Society supports this recommendation.

It has been noted that participants supported by strong advocates tend to have better plan outcomes.⁸ The Benevolent Society is pleased to see that the NSW Government reversed its decision to cut disability advocacy funding, and has introduced the Transitional Advocacy Funding Supplement from 1 July 2018. However, we would like the NSW Government to ensure that this funding continues beyond the initial two-year period if organisations and individuals still need help to advocate for their needs in the NDIS environment.

b) Plan implementation and review

Obtaining a suitable plan is just the first step. When some participants do get a plan approved they are then not sure what to actually do with them, and the plan gets put away in a drawer and forgotten about. This situation is reflected in the rates of under-utilisation of the NDIS, noted above. Many of our clients have not actually been into the NDIS portal and seen their plans.

Managing a plan requires ongoing skill and attention, which some participants may not have the experience or capacity for. Understanding what the plan provides can also be a challenge, with many participants who have not previously had to deal with the financial aspects of services shocked to see the actual costs of the supports they receive.

⁶ * Pseudonyms have been used instead of clients actual names throughout this submission

⁷ Commonwealth of Australia (2018), Joint Standing Committee of the NDIS: Transitional Arrangements for the NDIS, February 2018, p.39

⁸ Commonwealth of Australia (2018), p.40

Support coordination is important to help participants with varying capabilities to manage their plans. However, we have seen massive inconsistencies in how support coordination is allocated under NDIS plans. We also note that where plans have been updated or reviewed, allocation for support coordination has been decreased in the subsequent plan. In our view, the need for support coordination does not always diminish even though a participant may have been a party to the scheme for some time, particularly where the person's support needs are complex. In some cases, it is the coordination of supports that the participant receives which is keeping the participant stable and able to participate in everyday life, and it may take a long time to build their capacity in this area. Removing or reducing support coordination could be quite detrimental to their progress.

Recommendation:

The Benevolent Society recommends that:

1. The NSW Government engages with the NDIA to improve the NDIS planning process by:
 - (a) increasing the number of planners so participants can get face-to-face planning meetings in a timely way;
 - (b) ensuring the NDIA attracts and recruits people with understanding of, and experience with, people with disability to become NDIS planners to improve the planning process, and provides adequate training and supervision for planners; and
 - (c) requiring the NDIA's planners provide an explanation of why the recommendations of experienced clinicians are not included in a participant's plan.
2. The NSW Government continues to fund disability advocacy until it can demonstrate that these services are being fully funded to the same extent by the NDIS.

4.2.3 Communication issues: contacting the NDIA, accessibility and digital literacy

Our staff and our clients find it very difficult to communicate with the NDIA to get an informed and consistent answer in response to requests for information. Our staff, who are experienced disability practitioners, get frustrated by getting different answers from the NDIA depending on who they speak to. NDIA staff do not usually provide names or direct contact details so staff and participants can't confirm advice or request further information if they need to follow up. The Productivity Commission recommended that the Federal Government should lift the cap on staff at the NDIA to improve outcomes under the scheme- we would support this recommendation.

The Benevolent Society notes that accessibility of information and digital literacy is also an issue affecting participants' ability to navigate the system. The NDIS is based on the assumption that participants can navigate the system using digital web technology which in many instances is just not the case. The NDIS is also heavily dependent on written communication, which is not accessible for all people with disability. There is a long way to go for service-providers and the NDIA to prepare and disseminate information in a wide variety of formats and modalities to ensure it is accessible for all participants.

Case study: Contacting the NDIA

A Benevolent Society staff member called the NDIA and after waiting for over 45 minutes was told that the NDIA couldn't discuss the participant because the staff member was not listed as an employee of The Benevolent Society on the NDIS portal.

This happens regularly and appears to be an issue for large service providers as the NDIS portal can only show about 50 names for each organisation. Whilst all of our relevant staff are registered with the NDIA, their names do not show up on the portal, meaning they are not recognised as authorised to discuss NDIS clients with the NDIA when they make inquiries.

This issue is being taken up directly with the NDIA.

Recommendation:

The Benevolent Society recommends that:

3. The NSW Government requests that:
 - (a) the NDIA lifts the cap on the number of staff employed by the NDIA to improve the responsiveness of the NDIA to queries from clients and service providers;
 - (b) the NDIA appoints case managers or primary contact points for each participant so that participants and service providers can get consistent advice in relation to the participant's plan; and
 - (c) the NDIA uses a range of different channels and formats that are more accessible for people with disability to communicate key information on the scheme to NDIS participants and potential participants.

4.2.4 Availability of services

Another issue which limits an individual from exercising choice and control under the NDIS is the availability of services. The NDIS' individual-centred model assumes that services will be available for people who need them. For some people, for example people in regional and remote areas, the specialist services that they require under their NDIS plan are just not available in their local area.

4.2.5 Interface with other state-based services and between state and federal Governments

Having the right type of supports included under a plan is also critical to ensuring a person is getting the most out of the NDIS. Since the introduction of the scheme, there has been ongoing tension over funding between the state and Commonwealth Government which manifests in confusion about what types of services are included under the NDIS and what remains the responsibility of the state system. This is also impacted by the requirement for state government services to begin providing services that they have not been providing in the past and do not as yet have the capacity or systems to support. For example, it remains unclear if treatment for difficulty swallowing (dysphagia) for people with disability is covered by the NDIS or not.

Case study: Dysphagia

Dysphagia can have a real impact on a person's quality of life and their opportunities for meaningful participation in their community, but for people with disability the impact of dysphagia can be life-threatening.

The disability support sector is skilled, experienced and structured. Funding dysphagia support for people with disability as part of their NDIS plan enables this support to be delivered in line with the principles for therapeutic best practice, which recommend assessment in a person's day-to-day environment.

It also enables people with disability to exercise choice and control around how and from whom they receive support - which are underlying principles of the NDIS. Some planners are not including funding for treating dysphagia in NDIS plans because there has been discussion about whether or not it is included under the NDIS- even though a formal decision on this has not yet been made.

Recommendations:

The Benevolent Society recommends that:

4. The NSW Department of Health and the NDIA clarify the status of the treatment of dysphagia for people with disability within the NDIS and the state health system.

4.2.6 People with psychosocial disability

It has been acknowledged that there are major challenges with the transition to the NDIS for people with psychosocial disabilities.

Across NSW, as at May 2018 The Benevolent Society had approximately 314 clients under the Partners in Recovery (PIR) and 165 clients under Personal Helpers and Mentors (PHaMS) programs. Of these clients, only 35 had transferred to the NDIS - or just 7 per cent- with 15 clients awaiting a decision on their application to join the scheme.

The Benevolent Society is concerned with the alarmingly high rate of NDIS ineligibility for PHaMS clients; the inadequate allocation of services and support for those who are deemed eligible; and the ability of the service system to provide continuity of care beyond June 2019 when PHaMS is due to end.

Some of the difficulties with transition to the NDIS being faced by people with psychosocial disability include:

a) eligibility criteria and issues with the approach to mental health support

The process for determining eligibility under the NDIS requires people to emphasize their deficiencies - this is inconsistent with best practice in the mental health sector which is based on recovery-oriented practice. This means that to complete the forms with the best chance of success of access to the NDIS, staff need to adopt a 'deficit' approach and describe a client's worst days. This can be distressing for clients and has led some to choose not to apply for the NDIS.

b) standard forms and medical professionals

There appears to be a general lack of knowledge of the NDIS and the transition of mental health services amongst medical professionals. General Practitioners (GPs) and psychiatrists are an important part of the access journey to the NDIS for people with psychosocial disability. However, they need more information about the NDIS generally, and on what 'likely to be permanent' and 'likely to need support throughout their lifetime' means in the context of mental health.

Standard documentation for the NDIS is tailored to people with physical and intellectual disabilities and is difficult to adjust to reflect issues facing people with mental health problems. GPs and psychiatrists can modify the questions in the form to align better with psychosocial needs but some are not aware that they can do this or are refusing to do so, which leads to NDIS access requests being rejected.

The Benevolent Society has clients whose NDIS access requests have been refused on the basis of the GP reports which contained just one or two sentences.

Case study: Interaction with medical professionals during the transition to the NDIS

Jill went to the GP to complete the NDIS access request form. The doctor stated categories in the form were not relevant to her condition and therefore ticked 'no' to every section on the form. The GP did not know how to complete the form and did not have an example to follow. Jill then lost motivation to continue applying for the NDIS as it became too hard for her.

A support worker accompanied John to a GP visit in December 2016 to fill in the access request form. The doctor said that NDIS is only for significant disabilities and he did not think it would be for depression as people 'can get better'. He was not prepared to fill it in. The support worker enquired about making a referral to a psychiatrist or clinical psychologist however the doctor said he was not her regular doctor and did not feel that she needed a referral.

c) Impact on clients in remote and regional areas

The impact of the difficulties for clients with psychosocial disabilities transferring to the NDIS is acutely felt in remote and regional areas.

Case study: Mid-Western NSW

Mid-Western NSW has a population of 27,000 people over vast geographical distances. Our staff in this area are 1.5 hours from a set of traffic lights. Mudgee is a 1.5 hour drive from the larger regional town of Dubbo, a 2.5 hour drive to Orange and over 3.5 hour drive to Sydney. Services that are available that address the mental health needs of this community are very limited. People face access issues to mental health services due to challenges getting to the closest specialist or in-patient service and the limited choice of mental health providers in the local area.

In June last year, funding for PHaMS was cut on the assumption that clients would transfer to the NDIS. As a result of the funding cuts, The Benevolent Society had to reduce its staff numbers - we now only have 2.4 people servicing the whole area. To date approximately 30 PHaMS clients in Mudgee have submitted applications to the NDIS, 7 applications have returned eligible, 18 applications have returned ineligible and 5 are still awaiting an outcome. Of the 18 that were deemed ineligible 5 are currently appealing the decision and still awaiting an outcome.

Of the 7 who have received a package, there have been significant struggles in accessing supports within their plan locally, resulting in unspent funds and no service access. Some of our clients in Mudgee contact their PHaMS support workers up to 6 times a day at times of acute illness, and are not receiving the same level of access to supports within their NDIS plans.

The Benevolent Society has decided not to continue to provide core supports under NDIS for people with psychosocial disability because it is not financially viable, resulting in a significant financial loss to the organisation, when compared to operational running costs. At present, it is uncertain who we will be able to transfer our clients to because there are no other service providers in the area that have specialist expertise to work with this cohort.

Recommendation:

The Benevolent Society recommends that:

5. The NSW Department of Health undertake an education campaign to improve doctors' knowledge of the NDIS, and particularly of eligibility requirements under the NDIS for people with psychosocial disabilities.

6. The NSW Department of Health guarantee continuity of supports for people with psychosocial disability who are not eligible for the NDIS.

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

As noted above, there are certain cohorts of people with disability for whom the NDIS is not providing the level of service and support anticipated. People with intellectual disability and complex behaviour support needs face major challenges in exercising choice and control due to factors including the impact of the disability on the person's understanding of the NDIS pathway and their life options and goals; the impact of histories of trauma and a lack of adequate decisions and supports and advocacy whether from families or other supports.⁹

There are a number of other factors which combine to make the NDIS problematic for participants with complex support needs, including:

a) Cherry-picking clients

Given the NDIS operates in an open market environment, anecdotally we have seen that some providers are choosing not to provide services to people with complex needs. For example, we have seen in some cases organisations are choosing not to take on clients who require restrictive practices given this requires experienced staff to be trained in these practices which is a further cost to the organisation. As a result, sometimes clients with complex needs are being left behind under the new system.

The NDIA has announced it will release a special pathway for complex clients, but this has not yet been released.

b) No provider of last resort

In the past, the NSW Government under ADHC was equipped to deal with complex cases. ADHC would pull together all necessary services and provide wrap-around support to ensure that the person with disability got all the support they needed. Given the government no longer plays this role, and support depends on what is included in an individual's plan, there is no-one that people can turn to get assistance if all providers refuse to assist because they are 'too hard'.

In some cases, the NSW health system is stepping in as the provider of last resort, but this is far from ideal for all involved. We have seen cases of people with disability languishing in hospital because they cannot find accommodation services, or other support to help them. The health system does not want people with disability to occupy hospital beds long-term, and hospitals are often not set up to deal with the specific needs of people with disability with complex support needs.

The NDIA is expected to develop a provider of last resort policy but this has not yet been released.

c) Limited coordination and cooperation

⁹ Council for Intellectual Disability (2017), *A pathway through complexity*, 2017

Best practice in the disability sector is based on collaboration between organisations and between the component parts of service provision. Cross-service coordination is valuable for all participants, but especially for clients with complex support needs, and has been a feature of the disability sector in the past.

People with disability and complex support needs can require a high level of coordinated assistance to be able to draw together the type of support that they need. Whilst support coordination is available under the NDIS, the level of support coordination that NDIS participants receive varies greatly. As noted above, we have also seen that for participants that do manage to get a decent level of support coordination in their initial NDIS plan, it is often reduced in subsequent plans.

Given that plans generally do not include funding (or adequate funding) for specialist support coordination, on the rare occasion that services do come together to deal with complex problems facing participants, funding for clinician participation in such coordination meetings comes from the service line items within a client's plan. This means funding for the delivery of specialist clinical services may be reduced as a result. Plans often lack sufficient hours to enable this level of participation in collaborative planning as well as the discipline specific tasks required for the person.

Case study: Funding coordination under the NDIS

Jane's family was on the point of crisis and had been referred to the Integrated Service Response team established by the NSW Government. The Integrated Service Response team recommended three 4 hour sessions to bring together the relevant parties to work through the participant's many issues. However, participating in these coordinated planning sessions would mean that our psychologists would use up 12 hours from the participant's plan for coordination activities, that then couldn't be used for treating the client.

Information-sharing and coordination between organisations is also difficult in the NDIS open-market environment which is governed by competition law which deters 'collusion' in competitive markets. The disability service sector is still working out how to work best in this new environment and how to balance cooperation and coordination for the good of an individual client or the building of the market, against the provisions of competition law which covers the sector and disallows collusion.

d) No flexibility in plans to respond to crisis or change in circumstances

One major criticism of the NDIS is the fact that plans generally do not contain contingencies in the event that circumstances change drastically at short notice. For some people with disability, particularly those with complex support needs, a change in their personal circumstances (such as illness or death of a carer) or living arrangements (hospitalisation or incarceration) can have a profound effect on their health and ability to participate meaningfully in the community.

Currently, if there is a change in a participant's circumstances they have to apply for a formal plan review which can take several months- during which time their services and supports are suspended. This is particularly problematic if a plan review is needed at a time of crisis. We have had some clients in extremely high risk situations which have triggered us to request plan reviews. However, significant delays in waiting for these reviews to occur has

meant that we have been unable to provide services to these clients during this period of crisis because their plan was not operational whilst under review.

Case study: Need for flexibility and contingency in plans

The Benevolent Society requested a plan review for a client Bob, whose plan had run out and whose circumstances had changed. Bob's father had become terminally unwell and his mother had increasing health concerns which were impacting her capacity to provide care and support him. It took more than 4 months for the review to occur. In this time Bob's father passed away and Bob didn't have access to the behaviour support services that he needed to help him understand death and bereavement. At the same time, Bob's mother's health was deteriorating and Bob's living situation was at risk of breakdown. As the NDIS plan was under review, there was no access to respite, support coordination and other services to support him and his self-injury increased significantly during this time.

Recommendation:

The Benevolent Society recommends that:

7. The NSW Government encourage the NDIA to finalise and release the pathway for participants with complex support needs and the policy on 'provider of last resort'.
8. The NSW Government requests that the NDIA include funding for specialist support coordination in the NDIS plans of participants with complex support needs.
9. The NSW Government request that the NDIA ensure that plans for people with complex support needs include flexible, contingency funds to be used at times of placement breakdown or crisis, or to adapt to changing circumstances for NDIS participants.
10. The NSW Government embed the Integrated Service Response Project into the system long-term to assist with coordination of NDIS participants with complex support needs.

4.4 The effectiveness and impact of privatising government-run disability services

We recognise that there is some debate over the appropriateness of the term 'privatisation' in terms of the changes to the disability sector in NSW. We do not want to engage in that debate, but rather to jointly look for solution to the issues which are presenting in the current environment.

It is difficult to separate the issues of the transfer of disability services from government from the introduction of the NDIS – as the combination of both has had a profound impact on the sector (see section 4.6 on workforce).

Given that the majority of our disability services staff have come from the government as part of the transfer, they are well placed to compare the sector as it was previously, with the current state of disability services in NSW.

Having come from the government and been lifelong public servants, many of our staff look back fondly on ADHC and the type of long-term, wrap-around services that they were able to provide to clients and their families in that environment, compared to the time-limited, individual based support they can deliver under the NDIS.

Having had just over a year to adapt to the new environment, we are now seeing some of the gaps in the system which have emerged from having a centralised, national disability scheme without significant state based disability services.

These system wide gaps include:

- a) Coordination of, and support for the most difficult cases (see section 4.3);

- b) Lack of coordination across services across the sector (see section 4.3 (c));
- c) Work force issues (see section 4.6);
- d) Decrease in sector wide issues being addressed.

4.4.1 Decrease in sector wide coordination

Under the previous system, there were dedicated staff within ADHC who were drawn upon to consider the system wide impact of issues being faced by clients with disability. For example, if a person with disability was having problems that touched upon the criminal justice or health system, this team could look through the prism of the individual to see what issues across the system were impacting upon the individual. Under the NDIS, all assistance is individually focussed and there is no scope or funding to look beyond the individual to address systemic issues.

4.4.2 Stewardship and practice leadership of the sector

One of the strong points of the ADHC system was the practice leadership from FACS. The FACS team developed guides on clinical best practice and delivered training for the disability services sector across NSW. We understand that the NDIS Quality and Safeguards Commission will take over some of these functions, but that body is still getting up and running. In the meantime, there is a gap in terms of development of the disability community of practice in NSW.

4.4.3 Risk management and risk of market failure

The NSW Government as the provider of last resort under the pre-NDIS system would step in to deal with clients with the most complex support needs. In transferring management and delivery of disability services to non-government organisations the state no longer plays this role. The question which concerns The Benevolent Society is who manages and carries the risk of the failure to provide services for people if there is no longer a state-based safety net. We are already seeing that participants with complex support needs are struggling to find providers to assist them, and in many cases it is difficult to find accommodation when a placement breaks down for a client with complex support needs. In rural and remote communities there just may not be organisations with the right services or experience to meet the needs of a client, notwithstanding whether their plan includes funding for those services. In these cases, there is a real risk of market failure for some aspects of the disability market.

4.4.4 Specific gaps: voluntary out-of-home care

Following the transfer of disability services from FACS, some gaps in the system have become evident. This includes support in relation to voluntary relinquishment of children in the out-of-home care system.

Case study: Voluntary relinquishment into out-of-home care

‘Voluntary relinquishment’ is the term used to describe situations where families feel they are no longer able to safely care for their child and surrender the day-to-day care of their child to the state. The difficult decision to relinquish the care of a child is commonly driven by a family’s unmet need for services, in terms of facility-based respite or in-home support for a child with high support needs.¹⁰

¹⁰ Australian Child Rights Taskforce, *CRC25: Australian Child Rights Progress Report* (2016) p.18-19; Victorian Equal Opportunity and Human Rights Commission, *Desperate measures: The relinquishment of children with disability into state care in Victoria* (2012) p.30; National Disability Services, *Submission to the Senate Select Committee Inquiry on Out of Home Care* (2015).

The previous system provided a more holistic array of supports for families of children with disability.¹¹ The NDIS only provides specific supports that relate to a child's disability rather than broader support for the whole family. This can result in a family as a whole getting less support, which may push them closer towards crisis and relinquishment.

The implementation of the NDIS has created a lack of clarity as to who holds primary responsibility for the care of a child with disability who has been relinquished.

In NSW, the transfer of disability services to non-government providers prompted by the NDIS has drastically reduced the dedicated government staff resources and budget to manage these circumstances and the system capacity to provide emergency accommodation. Our staff report instances where statutory child protection services have declined to assume responsibility, indicating that voluntary relinquishment is not an option for these children because responsibility for their care and support needs falls under the NDIS.

Typically, these children have not been funded for ongoing daily residential care in their NDIS plans. This creates situations where NDIS respite service providers are rapidly expending the limited funding allocated for a child's respite accommodation and facing the predicament of how to provide unfunded accommodation to an extremely vulnerable young person.

Recommendation:

The Benevolent Society recommends that:

11. The NSW Government improve the interface between NSW child protection systems and the NDIS to ensure that children with high support needs have their rights to stable and secure accommodation, consistent support services and meaningful relationships with their families met.

4.5 The provision of support services, including accommodation services, for people with disability regardless of whether they are eligible or ineligible to participate in the NDIS

The Benevolent Society encourages both the NSW Government and the Commonwealth Government to look closely at the issue of accommodation for people with disability because the system under the NDIS is not working, particularly for people with complex support needs.

The shortage of general housing for people with disability is a long-standing issue, and the problem becomes more acute for people requiring accommodation in times of crisis. Notwithstanding that there is a shortage of available places in group homes, there are few incentives for investors and developers to build new homes to generate new places. There are also issues between the state government and service providers who operate accommodation regarding who covers the costs of renovations.

Under the previous system, service providers and government used to share information regarding availability of places in group homes but, as previously mentioned, under the NDIS' competitive market environment, informal information-sharing and cooperation between providers has decreased.

As a result, The Benevolent Society often struggles to find suitable accommodation for our clients. We currently have two clients who are homeless because they have been unable to find suitable accommodation. Another client has been released from hospital directly into a nursing home, against the client and the client's family's wishes. There is also a real gap in assistance for people

¹¹ National Disability Services, *Submission to the Senate Select Committee Inquiry on Out of Home Care* (2015) pp.7-8.

coming out of custody who need help finding appropriate accommodation. While some clients' NDIS plans do include support coordination, the allocated time for support coordination is rarely enough to match the actual time it takes to find a suitable accommodation placement.

People with very complex behaviour support needs often require modifications to their physical accommodation setting to maintain their safety as well as the safety of their co-residents and support staff. These modifications can be costly and were usually funded by state government in NSW. We are concerned that people's needs are not being met in this regard as a result of the NDIS funding structure and the current state government approach, resulting in very adverse outcomes including physical and psychological harm, hospitalisation, and incarceration.

Another housing related issues is the delay in resolving Supported Independent Living (SIL) funding for people with complex behaviour support needs. A number of clients with complex behaviour support needs often need to transition between accommodation settings and models. This often occurs at points of significant crisis and placement breakdown and the transition needs to occur with a high degree of urgency. We have seen that delays in resolving the SIL funding can have negative impacts for clients who may struggle to adapt to interim models of care. The difficulties with resolving SIL funding issues also holds up general plan review processes, and often leads to a break in behaviour support services and decreases the ability to adequately plan and stage transitions.

Recommendation:

The Benevolent Society recommends that:

12. The NSW Government introduce incentives for developers to build housing which can be used as group homes for people with disability.
13. The NSW Government request that the NDIA review its approach to Specialist Disability Accommodation funding to extend it to cover accommodation modifications for people with complex support needs.

4.6 Workforce issues impacting on the delivery of disability services

4.6.1 Workforce demand

It is well documented that the disability workforce will need to grow to support the NDIS. The Productivity Commission predicts that the NDIS workforce will need to more than double from 2014-15 to 2019-20, which means the NDIS will need about 70,000 additional disability support care workers (or about 1 in 5 of all new jobs created in Australia) over the transition period.¹²

National Disability Services (NDS) notes that the 'disability workforce isn't growing fast enough, demand for services will outpace market supply – impeding ...the scale of organisational change required'.¹³ The median age of the sector workforce is also an issue, as there is not a steady stream of workers coming through to replace workers approaching retirement age.

Governments at all levels should be doing more to grow the disability sector workforce, targeting new graduates and people in traditional areas of employment which may be threatened by increasing automation who may be willing to retrain into the disability sector.

¹² Productivity Commission 2017, p.32

¹³ National Disability Services (2017), *State of the Disability Sector Report 2017*.

4.6.2 Retaining staff

The transition to the NDIS has introduced a major change to the disability sector and the way that disability specialists work. We are seeing that it is increasingly difficult to attract and retain experienced disability workers in the NDIS environment.

The majority of The Benevolent Society's disability services staff have transferred across from FACS, so they have had to cope with two major change processes: the transition from the government to the non-government sector; and the transition to the NDIS for disability support services.

Not surprisingly, not all staff have been able to adapt to this amount of change in such a short amount of time. As a result, we have had a high-turnover of staff in our disability services. Some staff, who may have been reluctant participants in the transition in the first place, have subsequently decided to return to the government sector. For others, the cultural shift that has come from the transition to the NDIS has been too difficult to manage. Some staff have struggled to adapt from a system under which they could provide extensive, wrap-around, long-term support to people with disability and their families to a system under which each person's supports are limited to those available under their individual plan (which are often seen as inadequate to address the participant's needs). Many experienced staff who have worked in the sector for many years have found the new system, which involves significant administration and pressure to operate in a market environment, too difficult and have chosen to leave the disability sector altogether. The loss of a large cohort of experienced staff from the disability services sector is a major issue.

4.6.3 Graduate placement and training

The other major workforce issue in the sector following the transition of services to the non-government sector is the loss of a structured student placements program. The introduction of the NDIS has brought up new challenges for student supervisors and organisations in providing quality clinical placements.

In the past ADHC not only helped to coordinate the placement of approximately 150-200 students per year but also had a role in promoting consistent, high quality practice in the supervision of students. ADHC was responsible for fostering the work readiness of students to be able to support people with disability and promote the disability sector as a work choice upon graduation. Working in the disability sector takes specialised skills, and exposure to the sector through student placements is a good way to attract and retain students to the sector. However, with the government no longer playing a major role in the delivery of clinical services, that avenue for student placements and exposure to the sector is no longer available. Organisations, such as The Benevolent Society, continue to take on students, but not on the same scale as were previously placed through the FACS administered program.

The NDIS does not provide any subsidy or financial incentive to take on students or inexperienced staff who require supervision. In the current NDIS environment where organisations are under pressure to build sustainable business models which are reliant on productive utilisation of staff, there is limited time available for senior staff to supervise students or junior staff. It does not help that the NDIA does not allow organisations to bill clients for student consultations without the supervisor being present.

The question remains as to who is leading the development of the disability sector workforce. A disability skilled workforce is crucial to meet the needs and aspirations of people with disability and is ultimately needed for the success of the NDIS.

The Benevolent Society would like to see the establishment of a workforce development fund or other incentives for organisations to take on students to expose them to the disability sector and contribute to the development of the disability sector workforce. Funding to support the professional development of staff, which was a feature of the government system, is also not covered under the NDIS.

Recommendation:

The Benevolent Society recommends that:

14. the NSW Government and/or Commonwealth Government establish a Workforce Development Fund to provide grants and other financial incentives to encourage service providers to take on students in order to build the disability sector workforce.
15. The Workforce Development Fund should also include funding for organisations to support the professional development of staff.
16. The NSW Government request that the NDIA should develop guidelines to outline clear, reasonable and sufficient supervision requirements for students in the disability sector.

4.7 Challenges facing disability service providers and their sustainability

The Productivity Commission noted that the shift in business model from block funded to fee-for-service will be challenging for many service providers.¹⁴ The Benevolent Society has certainly found this to be the case.

4.7.1 Unbillable administration and issues with billing through the NDIS

One of the big challenges of the system which threatens the financial viability of providers is the high level of administration and unbillable work which comes under the NDIS. Service providers are only funded for billable contact hours with clients, however under the current NDIS system a lot of practitioners' time is taken up by other tasks such as interacting with the portal for billing, liaising with the NDIA, trying to find accommodation for clients and travel.

A major issue is the amount of time it takes to bill clients and sort out invoices which have been rejected by the NDIS portal without explanation. As noted above, when plans are reviewed, active plans are suspended until the review is finalised. During this time, service bookings are removed from the system, so any outstanding payments entered into the system for services provided under the plan before it was suspended for review are rejected without explanation. It takes a lot of time then to work back through the system to find out why bills are rejected. At this point, we often discover that we have delivered services which are no longer covered by a plan and therefore can't be charged against the scheme.

4.7.2 Price caps

¹⁴ Productivity Commission 2017, p.33

The impact of the NDIS pricing caps on the development of the disability services market has also been widely discussed in various recent inquiries and reports. Federal Parliament's Joint Standing Committee on the NDIS has already noted that

*many service providers are of the view that the current NDIS pricing caps have potential to negatively impact on the capacity for providers to deliver quality services.*¹⁵

NDIS reports that two-thirds of service providers worry they won't be able to provide services at NDIS prices.¹⁶ The Productivity Commission has also been quite critical of the NDIS price caps, stating that

*prices should be regulated as narrowly and for the least time possible; should be more granular; set at the state and territory level; evidence based; supported by clear and limited legislative authority.*¹⁷

One of the key pressures on service providers is the NDIS price caps.

The Benevolent Society believes in many cases, notwithstanding the recent price rises, that the current prices under the NDIS are insufficient to cover the reasonable costs of providing the services.

Most service providers are finding that the prices set by the NDIA do not cover the costs associated with delivering the service. In some instances, larger service providers are bearing the costs of delivering services under the NDIS price caps on the expectation that they can cover the losses until the NDIS prices become more reflective of actual costs of delivering the services or are deregulated.

In other cases, providers are choosing not to provide certain services or are withdrawing from providing services under the NDIS at all.

In any case, the success of the NDIS relies on a vibrant market which provides services to participants as needed. The pressure that service providers are facing in operating within the NDIS pricing model is deterring organisations from entering the scheme.

The other issue with the NDIS price cap is that at present, there is no way for participants to differentiate between services. In an unregulated market, price is usually an indicator of quality- however, in the nascent NDIS market when all services cost the same amount, there is no way for participants to determine which providers are delivering a quality service, and which are not.

There is not yet a mechanism where participants in the scheme can provide feedback on the quality of the services that they receive, so many participants sign up to providers without knowing what quality of services that they can expect.

The Benevolent Society welcomes the role the Quality and Safeguards Commission is expected to play in this space.

Case study: Delivery of support for people with psychosocial disability

The Benevolent Society, like many service providers, is finding it difficult to provide the type and quality of services required to meet the demand of clients with psychosocial disability, in accordance with the NDIS Price Guide. The delivery of services to people with psychosocial disability is different to some of the social supports offered under the NDIS and requires specialised and experienced staff, who need to be paid at an appropriate level.

In our experience, it is increasingly difficult to deliver the standard of service required in accordance with recovery based principles, retain workers with the requisite skills and experience to deliver quality services with integrity in line with the NDIA Price Guide. For this reason, we have recently made the

¹⁵ Commonwealth of Australia (Joint Standing Committee on the NDIS) 2018.

¹⁶ National Disability Services, 2017.

¹⁷ Productivity Commission, 2017 p.33.

incredibly difficult decision that it is not financially viable to continue to deliver psychosocial support under the NDIS, outside of our current contractual arrangements within Partners In Recovery.

We understand that this may mean that there are less organisations providing these types of services, particularly in rural and remote communities, but until the NDIA recognises the actual costs of delivering these services, particularly in rural and remote communities, it will not be financially viable for organisations to continue to provide these services.

4.7.3 Insufficient coverage of travel costs

The insufficient coverage of travel costs is also an ongoing issue under the NDIS. There have been some changes to enable service providers to claim more time for travelling between clients - but the allowances are still insufficient to cover the level of travel that staff need to do in busy metropolitan areas, and completely inadequate for travel in regional and remote locations. There is also no funding method which allows for travel to support state-wide specialist service practitioners who are required to travel across the state to treat people with the most complex support needs where local expertise is not available, as the NDIS does not cover air travel and assumes service providers will be reasonably proximate to their clients.

Case Study 3: Insufficient allocation for travel costs

The Benevolent Society provides services to a child with complex support needs within a family whose support needs are also very complex. The family have been unable to find a service provider in their area who can provide the support they need, so The Benevolent Society makes a 230 km round trip to support the family. Under the travel criteria at the time, the annual travel claim cap would have been exhausted in 3 visits but there are no other organisations nearby that can meet the family's needs or with which the family wishes to work. As the travel costs cap is exhausted after three visits, The Benevolent Society must bear the travel costs for additional visits.

Recommendation:

The Benevolent Society recommends that:

17. The NSW Government request that the NDIA resolve issues with the NDIS portal and the inability of service providers to bill for services delivered to a client prior to a plan review. This should include the development of a notification system for clients and service providers alerting them when a plan review process is underway.
18. The NSW Government request that the NDIA provides accessible information to participants and the public about the providers available in the market and indicators of participant satisfaction with those providers.
19. The NSW Government request that the NDIA review travel costs under the NDIS, with consideration of the impacts on service providers' ability to provide services under the NDIS in rural and remote areas of NSW.
20. Travel costs include funding to cover outreach from specialists where services are not available in an area, to increase choice and outcomes for participants, and to minimise harm from a lack of tailored services available.

4.8 Any other related matters

a) Lack of funding for research and for practice improvement

One of the gaps in the system that concerns The Benevolent Society is the lack of funding for research and innovation. Practitioners in the sector and service providers are always looking for ways to deliver services for people in more efficient and effective ways.

Recommendation:

21. The Benevolent Society recommends that the NSW and/or the Commonwealth Government commit funding for research and innovation in the disability service sector.