



Physical Disability Council of NSW
Ordinary People Ordinary Lives

Submission for Joint Standing Committee on the National
Disability Insurance Scheme

Transitional Arrangements for the NDIS

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Who is the Physical Disability Council of NSW?

The Physical Disability Council of NSW (PDCN) is the peak body representing people with physical disabilities across New South Wales. This includes people with a range of physical disability issues, from young children and their representatives to aged people, who are from a wide range of socio-economic circumstances and live in metropolitan, rural and regional areas of NSW.

Our core function is to influence and advocate for the achievement of systemic change to ensure the rights of all people with a physical disability are improved and upheld.

The objectives of PDCN are:

- To educate, inform and assist people with physical disabilities in NSW about the range of services, structure and programs available that enable their full participation, equality of opportunity and equality of citizenship.
- To develop the capacity of people with physical disability in NSW to identify their own goals, and the confidence to develop a pathway to achieving their goals (i.e: self-advocate).
- To educate and inform stakeholders (ie: about the needs of people with a physical disability) so they are able to achieve and maintain full participation, equality of opportunity and equality of citizenship.

Introduction:

The Physical Disability Council of NSW (PDCN) appreciates the opportunity to provide feedback on transitional arrangements for the NDIS to the joint standing committee on the National Disability Insurance Scheme. In this submission PDCN will provide comment on the roll out of the NDIS in relation to the terms of reference. PDCN will also address the issues created by future funding arrangements for advocacy and peak representative organisations.

The following submission will be separated to reflect the terms of reference.

a) the boundaries and interface of NDIS service provision, and other non-NDIS service provision, with particular reference to health, education and transport services;

PDCN believes clearer information on the funding and delivery responsibilities of the NDIS and non-NDIS service systems, in relation to health, education and transport is essential to ensure NDIS participants do not encounter gaps in the services they receive as they transition into the scheme.

Issues arising from the interface between the NDIS and non-NDIS service provision are already evident in the provision of transport in NDIS plans. Prior to the roll out of the NDIS, community transport services were heavily subsidised for the people with disability whom used these services through a number of Government funded programs (such as the Community Transport Program and Community Care Support Program through Transport for NSW)

The transition to individualised funding within NDIS plans and the removal of this significant subsidisation has increased Community transport organisation trip prices considerably (to market price). In conjunction with the introduction of new forms of transport charged at market rates, PDCN is concerned that funding for transport in NDIS plans at the current set levels will be insufficient to cover these increases and this will severely limit the ability of NDIS participants to access community and mainstream services (such as employment and education).

This issue has already been challenged by the court case of “Liam McGarrigal vs NDIS”. Mr McGarrigal who lives in Moriac, Victoria was receiving funding for transport in his NDIS plan to cover his travel to work and to a group program as he is unable to drive and does not have access to public transport. Under his NDIS plan, the National Disability Insurance Agency (NDIA) was providing Mr. McGarrigal with \$11 850, which represented approximately 75% of the annual cost of \$15 850 required to pay for taxis and transport¹. The court found that it was not permissible for the NDIA to partially fund a support identified to be reasonable and necessary in a participant’s plan.

Individuals with disabilities living in rural or remote areas, where transport infrastructure is non-existent or services are infrequent, and where they may be required to travel long distances to access services, will be disproportionately disadvantaged by the current insufficient funding for travel, even taking into account the special additional transport allowances able to be given in these circumstances.

Ongoing collaboration between the NDIS and other mainstream supports is required to ensure these systems run efficiently and people with disabilities are not left without essential services.

In the area of health PDCN are aware of current concerns when it becomes time to transition out of hospital into the community, for example in the interface between the health system and the NDIS when working to prepare a patient for exiting hospital to private (or other) residence and arranging care needs or for an NDIS plan in readiness, particularly in the case of newly diagnosed or injured individuals.

Similar issues are arising in the education sphere, where ‘in school supports’ are being lost to some students with disability, as the two systems delegate responsibility for costs/provision to each other.

b) the consistency of NDIS plans and delivery of NDIS and other services for people with disabilities across Australia;

PDCN has observed issues with the consistency of initial NDIS plans received by participants as the NDIS roll out has occurred across New South Wales. Through our capacity building programs PDCN has followed several NDIS participants from pre-planning to plan implementation. In PDCN’s opinion the variation in the outcome of initial plans, including the

¹ ¹ Federal Court of Australia, McGarrigle v National Disability Insurance Agency [2017] FCA 308, 2007, <http://www.judgments.fedcourt.gov.au/judgments/Judgments/fca/single/2017/2017fca0308> (accessed 16/08/2017)

allocation of reasonable and necessary supports is due to the competency of planners and the time and resources allocated for planning.

NDIS participants have reported planners having insufficient disability knowledge and lacking the skills and experience needed to navigate planning conversations that cover all possible support needs under the NDIS. The outcome of planning conversations has been less successful where participants have complex support needs or planning conversations have not been arranged to allow equal access for individuals with specific communication needs.

The mode of planning meetings must be carefully considered as this has a significant impact on the quality of participants initial plans. Several participants have reported to PDCN that their planning meetings were conducted over the phone.

PDCN feels face to face interviews are more appropriate for most participants, especially those with complex support needs as phone conversations will not be sufficient in determining reasonable and necessary supports. Planning conversations are more successful when an individual's support network, including family members or support workers, is involved and the meeting allows for the sharing of important preparatory documents. Interviews conducted over the phone also prevent the planner from being about to utilise physical cues that would assist in thoroughly assessing an individuals need for supports and equipment.

In addition, planning over the phone if conducted with a carer or family member rather than the person with disability is not person centred and undermines the participant's ownership of their plan.

Another issue with the delivery of NDIS plans has been the introduction of 'My First Plan' in early 2017. PDCN appreciates that the NDIA was seeking to streamline the process of NDIS transition and reduce the burden for participants joining the scheme who felt unprepared for the shift to funding arrangements based on goals. However, limiting NDIS participants to two goals, or just onboarding them with only what is currently in place in terms of service, has disadvantaged individuals who are aware of the supports they require, as well as the goals they wished to achieve, and were well prepared for the introduction of the scheme. My First Plan has taken choice and control away from individuals who have the expertise to determine their goals and their own readiness to work towards these goals.

The complexity of the NDIS appeals process and long wait times for plan reviews has been repeatedly stated as an issue. Currently if a participant identifies an unmet support need in their plan they must request a formal review (within a set time period) or wait until their annual plan review. Implementing a more consultative process with greater liaison between participants and local area coordinators (LACs) would enable support gaps to be raised and comprehensively addressed during the construction of plans, making the planning process more efficient and reducing the overall number of plan reviews requested by NDIS participants.

PDCN acknowledges that this is a complex process that requires a high degree of skill and time to complete effectively, and that due to the short time frame in which 140,000 people with disability were to be onboard in order to meet scheduled deadlines, LACs have also struggled to be able to find sufficient time to comprehensively plan with participants, and are rarely able to commit to the second half of their role, being assisting new entrants with the implementation of plans once received.

The effective delivery of the NDIS has been impacted by LACs not having the resources to assist NDIS participants to understand and implement their plans. PDCN has observed many participants who were in possession of their NDIS plan for several months before utilising any of their funding. PDCN believes this is due to a lack of guidance from LACs combined with participants limited understanding of the plan itself, specifically the difference between core, capital and capacity building supports, plan management options and how supports can be purchased through the NDIS portal.

This matter has been further exacerbated by NDIS participants not receiving necessary funding for support coordination or funding being inadequate to meet their needs. Support coordination is a capacity building support an NDIS participant may receive to assist with implementing and monitoring the supports in their plan. A support coordinator can assist a participant to understand their service options, negotiate with service providers, arrange assessments or to link to mainstream or community services (i.e. housing, education, transport, health).

If an NDIS participant has complex support needs and requires this level of assistance they are eligible to receive funding for support coordination. PDCN feels this has not been clearly communicated by LACs during planning conversations, with reports that individuals have been told they will only be able to receive funding for plan management or support coordination.

This has led to NDIS participants who are not receiving support coordination yet do not have the skills or support that would be essential to use their individualised funding.

Additionally, whilst the cohort of whom PDCN represent, those with physical disabilities, may well be seen as some of the most capable and likely to understand and manage their plans, conversations with our members highlights the fact that the NDIS is a new and unknown scheme for ALL participants, and even those whom are intelligent, highly functioning individuals are requiring support in order to understand and navigate this new regime, and would benefit from a small amount of time limited support coordination.

c) the rollout of the Information, Linkages and Capacity Building Program; and

The information, linkages and capacity building program will be targeting four million people with disability and 800,000 of their primary carers² around Australia. Community based programs will be available to both individuals who are receiving an NDIS plan and to people with disabilities who are not receiving individually funded supports. PDCN is concerned that funding allocated to the ILC program will be inadequate to support the number of people who will be accessing services.

The ILC has not been present in the NDIS trial sites and the timing of its roll out has been poorly planned. PDCN believes the ILC should have been already in place in districts before the NDIS roll out, in order to provide participants with greater support during the NDIS transition.

Under the ILC arrangement, many services that are currently funded to provide support, will be required to lodge an expression of interest for future funding. Given the estimated numbers of people who will be accessing ILC services, the number of grants available for organisations is likely to be insufficient to address community needs for both NDIS funded participants and people with a disability who will not access the NDIS.

² Australian Government, Productivity Commission Inquiry report: Disability, Care and Support, volume 1, 2011, page 160

If people are not receiving adequate support through ILC programs, cost pressures on the NDIS will increase as people with disability (both NDIS participants and non-participants) will be less likely to utilise mainstream services.

Additionally, as documented in the ILC commissioning framework³ local area coordinators have a multifaced role to play in the implementation of the NDIS. Combined with providing support and information to people in receipt of individualised funding packages, LACs will have significant responsibilities including providing referrals and information to all members of the community with disabilities and community development to assist mainstream services to be more inclusive. With LACs experiencing high demands on their time with the implementation of planning work it is conceivable that they do not have the capacity to perform this part of their role.

If LACs do not have the resources to take a proactive approach in outreach, particularly engaging individuals who are the socially isolated or from culturally and linguistically diverse backgrounds there will be individuals with disability, not eligible for the NDIS but requiring support, who do not seek out LAC assistance and will miss out on vital services.

d) any other related matters.

Funding for Advocacy and peak representational organisations

As of 30 June 2018, all NSW funding for disability advocacy, information and representative organisations will be transferred to fund the NDIS. Following a review, the current funding under the National Disability Advocacy Program (NDAP) has been guaranteed until 30 June 2020, but only to the organisations currently funded within this program, and with no monetary increase. However, this will still leave a majority of NSW state funded organisations under or completely unfunded. The future funding of peak bodies and disability representative organisations is uncertain and PDCN believes that this will have a direct impact on the NDIS.

PDCN's opinion is that continued funding for peak organisations to provide systemic advocacy, independent information and representation for people living with disability in New South Wales is essential to meet the objectives of the NDIS.

The Disability Reform Council has the responsibility of providing advice to the Council for Australian Governments (COAG) on policy issues relevant to the roll out of the full scheme including future advocacy arrangements. COAG seeks to ensure that alongside the roll out of the NDIS the policy outcomes of the National Disability Strategy (NDS) are upheld. The National Disability Strategy has made a commitment to advocacy in line with their second policy outcome area, ensuring that people with disability have their rights promoted, upheld and protected⁴.

The NDS states "disability advocacy services enable and support people with disability to safeguard their rights and overcome barriers that impact on their ability to participate in the community"⁵

³ National Disability Insurance Agency, Information, Linkages and Capacity Building Commission Framework, 2016, page 11

⁴ Commonwealth of Australia, National Disability Strategy 2010- 2020, page 40

⁵ Ibid, page 40

The council will also advise COAG on policy matters as they relate to the NDIS Act. As outlined in the act, its general principles guiding action supports the continued work of disability representative organisations, such as PDCN. The act recognises that the inherent knowledge and lived experience of people with disabilities should be acknowledged and respected⁶.

Systemic advocacy undertaken by peak bodies such as PDCN, ensures the inclusion and full participation of people with disabilities in society by identifying and addressing issues on a larger scale than is possible with individual advocacy, or at times by an individual alone. Additionally, hundreds of years' worth of expertise, community knowledge and advice to government and collaborative relationships will be lost should these organisations no longer be funded. As is the case in this submission, Government processes frequently rely on representative organisations for feedback and direction (i.e. progress reports/submissions).

The ongoing modification and growth of the NDIS requires consultation with stakeholders to preemptively address systemic issues. NDIS participants will not be able to fully realise the tenets of choice and control if there are barriers to their full inclusion in society.

Much of the work our organisations undertake and supports falls outside of the remit of the NDIS, and includes state based issues across the broader mainstreams arena of education, employment, health, access and human rights.

In addition, PDCN is concerned about the lack of support available to assist participants to understand and navigate the changes as they move onto the scheme. If advocacy is only available on a user pays basis through individualised NDIS plans, those with insufficient funding or without individual funded supports (IFS) who are only accessing Information, Linkages and Capacity building programs will not be able to access advocacy services.

It is important to note that this funding loss will occur not only in NSW but in other States and Territories as they too fully implement the NDIS within their own jurisdictions.

The introduction of the NSW Quality and Safeguarding framework as part of the NDIS will also need to be tested as it is rolled out to ensure that it meets its objectives and issues are identified and addressed. Without funding for advocacy organisations there will be an absence of independent safeguards to ensure that people with disabilities can access the systems of support provided under the framework.

⁶ Australian Government, National Disability Insurance Scheme Act, 2013, part 2- Objects and Principals.