October 20, 2017

Joint Standing Committee on the National Disability Insurance Scheme (NDIS)

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Parliament House

Canberra ACT 2600

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Dear Committee,

Re: Inquiry into Transitional Arrangements for the NDIS

People with Disability Australia (PWDA) thank the Committee for the opportunity to provide evidence at the public hearing regarding transitional arrangements for the NDIS on Tuesday 3rd October 2017.

PWDA is a leading disability rights, advocacy and representative organisation of and for all people with disability. We are a NSW and national cross-disability peak representative organisation and member of Disabled Peoples Organisations Australia (DPO Australia). We represent the interests of people with all kinds of disability. We are a non-profit, non-government organisation. PWDA’s primary membership is made up of people with disability and organisations primarily constituted by people with disability. We have a vision of a socially just, accessible and inclusive community, in which the human rights, belonging, contribution, potential and diversity of all people with disability are recognised, respected and celebrated with pride.

I am writing to follow up on the verbal evidence provided by myself and Jen Ruse, Manager NDIS Appeals. As we stated in our evidence, PWDA members and clients have experienced numerous issues relating to the NDIS transitional arrangements.

These issues include; gaps in supports, denial of funded support services or equipment, and inconsistent or inadequate plans. In some cases, these issues have been life threatening or are bringing individuals or families to crisis. We made several points at the hearing which we outline in detail below:

**Interface**

A number of PWDA’s individual advocacy clients have been denied access to the NDIS because planners have claimed that their required supports are best met by the health system. This is despite these clients requiring ongoing, specific health resources to facilitate and maintain their life in the community.

This would make these supports the responsibility of the NDIS, as described in *the Principles to Determine Responsibilities of NDIS and Other Services* (henceforth, the *Applied Principles*).[[1]](#footnote-1) The NDIA’s operational guidelines for planning provide some clarity and examples of the types of supports people can expect to be funded by the NDIS versus the health system. The *Appendix* to the *Operational Guidelines: Planning* states that the following supports, dependent on purpose, may be funded by the NDIS:

*Care and supervision by clinically trained staff, including delegated care:*

* *Supports which, dependent on their purpose, may be funded by the NDIS or other parties* 
  + - *NDIS: where this is required because of the participant’s functional impairment and integrally connected to the participant’s support needs to live independently and to participate in education and employment (e.g. supervision of delegated care for ongoing high care needs, such as PEG feeding, catheter changes, skin integrity checks or tracheostomy tube changes).[[2]](#footnote-2)*

Despite the delineation of support provision as outlined in the *Operational Guidelines*, PWDA have seen cases where these guidelines are clearly not understood or followed by Planners and Local Area Coordinators (LACs).

PWDA has supported two clients for whom the NDIS failure to fund Registered Nurses (RN) to change tracheostomy tubes has led to them being at risk of suffocation. EnableNSW, the NSW government equipment provider, funds the change of tracheostomy; Southern Cross Health is funded by the NDIS to source the RN or care worker. The failure for either NDIS or NSW Health to fund the RN for the tracheostomy change more than once a fortnight, despite this being needed to maintain the client’s work and life, has led to clients being at risk.

In addition, the Department of Health (through EnableNSW) and the NDIS fund different parts of the apparatus for the clients’ tracheostomy and catheter, meaning sometimes orders for parts do not match up, and additional administration is required from the participant.

The *Applied Principles* state that:

*The NDIS and the health system will work together at the local level to plan and coordinate streamlined care for individuals requiring both health and disability services recognising that both inputs may be required at the same time or that there is a need to ensure a smooth transition from one to the other.[[3]](#footnote-3)*

PWDA are concerned that this streamlined planning and delivery of care is being compromised.

*We strongly recommend that the NDIA consistently train Planners on the NDIS’s own operational guidelines regarding the responsibilities of NDIS to fund health support needs when this is connected to the participant’s needs to live independently. Further, we recommend that improved measures for co-ordinating cross-disciplinary care be implemented.*

**Delivery of plans**

PWDA has consistently raised concerns regarding the quality of the NDIS planning process.[[4]](#footnote-4) As the scheme moves to full roll out, we are increasingly seeing the quality of NDIS plans being compromised. The principal of people with disability overseeing and contributing to the outcomes of the NDIS is at stake in this issue.

*We recommend the NDIS implement a step in the planning process through which participants are able to check their goals, support needs and circumstances prior to a final plan being produced. This would enable participants to have more control over the quality of their plans, would likely mean more accurate and high quality plans, and therefore less appeals and reviews.*

**Gaps created by the withdrawal of state based services**

PWDA members and clients have experienced a number of gaps as the NDIS has rolled out and state governments have withdrawn services. We are seeing circumstances in which services are being withdrawn with no appropriate alternative, inadequately replaced, or not supplied. Some children with disability are not being adequately supported in the home and parents feel they may have to relinquish care, or people as young as 53 have to use aged care supports.

PWDA are very concerned about emerging issues relating to the lack of clarity around transition from state to NDIS services. The internal cost shifting that is occurring between NDIA and state based services will lead to considerable personal impact on individuals and families, as well as cost implications across different sectors.

We welcome the recent release of the Productivity Commission’s report into NDIS costs. This report provides a comprehensive response to many of the issues that PWDA has consistently raised on behalf of our members. We look forward to providing further input to this Committee on the implementation of recommendations of the report as the transition continues to roll out across the states.

In particular, we note that the Commission is concerned about quality of the NDIS planning processes, the early withdrawal of state based services where NDIS markets are not yet mature enough to respond, and the need for the NDIA to release the Provider of Last Resort Policy and Market Intervention Framework.

We also note that the Productivity Commission has recommended that states and territories maintain funding for state based advocacy services to 2020, at which time an evaluation will be undertaken to determine ongoing funding arrangements. We strongly support this recommendation and urge the Committee to draw attention to the critical gap in advocacy services that will be left after state funding ceases (in NSW this is will occur at the end of June 2018).

We thank you once again for the opportunity to provide evidence to the inquiry. To provide further context to the transition issues that are occurring, we will make a more detailed submission to the General Issues Inquiry in due course.

Meanwhile we are happy to be in touch with Committee Members and would welcome the opportunity to elaborate further on any issues raised in this letter.

Kind regards,



Dr Meg Clement-Couzner

**Senior Policy Officer: NDIS**

1. NDIA, 2015, *Principles to Determine Responsibilities of NDIS and Other Services*, available from: <https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf> [↑](#footnote-ref-1)
2. NDIA, *Operational Guidelines: Planning*, *Appendix 1, Health (excluding mental health)*, available from: <https://www.ndis.gov.au/operational-guideline/planning/appendix.html#health> [↑](#footnote-ref-2)
3. NDIA, 2015, *Principles to Determine Responsibilities of NDIS and Other Services*, available from: <https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf> [↑](#footnote-ref-3)
4. Disabled People’s Organisation Australia, of which PWDA is a member, has raised this issue multiple times, including in its Submission to the Productivity Commissionreview of NDIS costs, available at: <http://dpoa.org.au/submission-productivity-commission-inquiry-national-disability-insurance-scheme-ndis-costs/> [↑](#footnote-ref-4)