Physical Disability Council of NSW
Ordinary People Ordinary Lives

Submission for the National Disability Insurance Agency (NDIA)

**Proposal for National Disability Insurance Scheme
Quality and Safeguarding Framework Consultation Paper**

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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

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 (ie: 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.

Overview

The Physical Disability Council of NSW appreciates the opportunity to consider, and make comment to the National Disability Insurance Scheme consultation paper on *Proposal for a National Disability Insurance Scheme Quality and Safeguard Framework* (February 2015).

PDCN will not be making comments on all the questions raised, but will respond to the following sections, where we can add contribution to the discussion.

- Access to information

- Building Participants Capacity to Exercise Choice and Control

- Restrictive Practices

- Ensuring Staff are Safe to Work

- Provider Registration

- Handling Complaints

Comment: Access to Information

> *Q.* What are the most important features of an NDIS information system for participants?

PDCN supports participants having access to high-quality, meaningful and credible information about support options and providers. Without this, people cannot exercise choice and control.

Access to information is particularly important in helping participants make informed decisions, and in developing self-advocacy[1]. However, information relating to the NDIS needs to be provided in an accessible format, readily available and provided in their preferred communication format. For example, but not limited to: Braille, or Easy English. For Culturally and Linguistically Diverse (CALD) populations, information should be provided in the participant's preferred language.

The Consultation paper places an emphasis on the use of social media and web based information, however little consideration towards face-to-face contact. PDCN suggests the NDIS Information System find a balance between the use of online strategies and more traditional (for example: face-to-face contact) forms communications to relay information.

Our submission, *NDIA Information, Linkages and Capacity Building* (2015) highlights 'the use of online communication technologies should complement rather than replace more traditional forms of communications'[2]. Not all people with disability have the resources to access online communications, therefore face-to-face or traditional forms of communications provide greater opportunity and ease of access to information for these people.

People who are living in rural or remote areas may also have limited internet coverage. To provide an example, one member discussed how they would complete a 2 hour round trip to make use of their nearest local internet access, for this person a reliance on online content is not appropriate. At times due to ill health, this person could not make this trip and so could wait weeks to access online information.[3]

The consultation paper has proposed a few strategies to resolve this, such as using support 'expos' to make participants aware of information and services that could be of benefit to them.

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[1] NDIS (2015) Consultation Paper: *Proposal for a National Disability Insurance Scheme Quality and Safeguarding Framework*, February 2015, p.12

[2] PDCN (2015) Submission: *NDIA Information, Linkages and Capacity Building*, March 2015, p.3

[3] PDCN (2014). Telephone Statistics

PDCN support the suggestion of expos, however considerations would need to be made around the frequency, time and location of these expos, ensuring the expos are in locations frequently enough, and at times that will be beneficial to people in those areas.

Strategic processes should be in place to promote and disseminate information about expos, promoting details widely and with adequate notice to ensure people can make the necessary arrangements to attend. On occasions individuals have mentioned they have not been aware of events taking place in their area, and so have not been able to attend, with a significant time gap until the next similar event is in their area[4].

An option could be to host online booths in community centres/towns, so that participants can readily access information without having to wait for it. If this option were to be considered, information would need to be kept up to date.

Recommendation:

1. **Information share both online and using face to face strategies, to allow access to information for those who have limited access to online communication technologies**

2. **All information and details of expos to be provided in multiple accessible formats, and languages.**

3. **Consider options to have an information source as a constant feature in towns/communities, to avoid delays waiting for an expo to be available in a person's area**

> *Q.* How can the information system be designed to ensure accessibility?

The NDIS information system should consider participant needs in accessing information. Article 21 of the *United Nations Convention on the Rights of People with Disability* (2006) states that:

> *'appropriate measures be taken to ensure people with disabilities exercise their right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice[5]'.*

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[4] PDCN (2014). Telephone Statistics

[5] UN (2006) *Convention on the Rights of People with Disabilities,* United Nations, Article 21.

To ensure accessibility, information must be provided in an accessible format, through accessible technologies, and in the participant's preferred communication style. It is essential this is done in timely manner and without cost, so participants can readily access information. Participants should also be made aware where alternative accessible formats exist.

Independent advocacy options and services which are not confined to Government agencies and services are also an important part of making information accessible and readily available for participants. Whilst for people with disability in NSW, Ability Links currently acts as a first point of contact in local communities assisting with person centred pathways, an independent advocacy option also needs to be available to assist with everyday issues, where people need to navigate complex and multiple services and systems which are often running in silo (for example housing, health, justice)[6]. People who do not receive advocacy and information support could enter situations where they feel they 'do not know where to go'. This could have negative impact in their lives, on achieving their goals and aspirations, as well as inhibit their inclusion in everyday life. The benefits of this support can avoid costly escalation and also identify opportunities for improvement to make systems work better together.

Recommendation:

4. **Utilise pre-existing advocacy services that are available in each state or territory to support people with everyday issues/information requests**

> *Q.* What would be the benefits and risks of enabling participants to share information, for example, through online forums, consumer ratings of providers and other means?

There are a number of benefits and risks associated with participants sharing information online. In terms of privacy and confidentiality, participants need to be aware of and understand their rights to privacy and confidentiality.

PDCN recommends the NDIA design a policy or service user agreement that details how shared information is used. This could include safeguards on security, safety procedures and when and how information is shared.

Sharing information online can make people with disability vulnerable if their identity is not protected. People with disability have the right and the choice whether or not to to disclose information about their disability. The NDIA should design a secure

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[6] Centre for Disability Research and Policy, University of Sydney (CDRP) and Young People in Nursing Homes National Alliance (YPINHNA) 2014. *Service coordination for people with high and complex needs: Harnessing existing cross-sector evidence and knowledge*,

forum/outlet where people can anonymously share information without harm and protect their rights of self-disclosure relating to their disability.

Disseminating individually targeted information requires participant consent, however it has underlying risks and benefit. In reference to the Consultation Paper, this type of information would be beneficial in terms of notifying participants of new providers in their community, or evidence on effective types of supports[7]. PDCN has some concern where the paper discusses 'targeted information'[8], this could be assumed as not being person centred, as a person is receiving information on an assumption made by the NDIA of what information they would want to know. Instead PDCN suggests it would be preferable to have an 'opt in' approach where the person has the ability to choose what information they want to receive.

Recommendation:

5. **Ensure information is provided to the participant on their rights regarding privacy and confidentiality.**

6. **Where online strategies are used, ensure stringent policies are implemented to protect the identity of the participant, and about how data is used and disseminated.**

7. **Recommend online forums have advanced security settings to avoid risks associated with online threat, such as hacking or "trolling".**

8. **Implement an 'opt in' approach to information dissemination, to avoid an individual receiving information based on assumption.**

Comment: Building Participants Capacity to Exercise Choice and Control

> *Q.* What can be done to support people with a limited number of family and friends?

People with a limited number of family and friends face additional challenges in exercising choice and control. They may face unique levels of vulnerability in terms of their health, or not having a strong support network. To address this, a better understanding and engagement with local communities and providers is required[9]. In

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[7] NDIS (2015) Consultation Paper: *Proposal for a National Disability Insurance Scheme Quality and Safeguarding Framework*, February 2015, p.14

[8] Ibid

[9] Kashmira Gander (2015) 'Loneliness maps' should be used to help the most isolated people, report advises. *The Independent,* Wednesday 8 April 2015, http://www.independent.co.uk/life-style/health-and-

addition, better communication, collaboration and cooperation between advocacy services, community linkages and providers is needed, to identify, reach and support participants with limited connections, or who are dealing with isolation[10].

Another suggestion, is the University of Kent's Campaign to End Loneliness (UK), where maps are used to identify the nation's loneliest people via location[11]. Whilst this is mostly targeted at elderly people, it may also be useful in Australia. In the campaign services, advocacy organisations and mentoring support networks reach out to support these individuals.

The Consultation Paper's proposed Safeguarding Framework identifies the development of both developmental and individual safeguards. This is particularly crucial in minimising risks faced by participants facing isolation. PDCN recognises that participants should exercise their capacity in determining their own safeguards. However, additional developmental safeguards need to be implemented to help them build and exercise this capacity. For example, Independent Advocacy Services or Community Linkage Services could provide participants with face-to-face-support and tools in helping them exercise choice. These types of services could be incredibly valuable in providing the right information, at the right time and in the right format[12]. Good information provision and supports assist people to exercise good choice and control[13].

Recommendation:

9. **Introduce developmental safeguards to identify, reach and support participants affected by isolation or limited support networks.**

10. **Support the continued block funding of the current strong advocacy sector to allow continued assistance to people with a disability to develop their own capacity to direct their own supports.**

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families/health-news/loneliness-maps-should-be-used-to-help-the-most-isolated-people-report-advises-10163696.html

[10] Ibid

[11] Campaign to End Loneliness: Connections in Older Age (2015), accessed 16 April 2015 at http://www.campaigntoendloneliness.org/

[12] NSW Disability Network Forum (2015) *Position Paper*, p.9.

[13] Ibid

Comment: Provider Registration

> *Q.* Considering the options described above, which option would provide the best assurance for:
> - Providers?
> - Participants?
>
> **Q.** Should the approach to registration depend on the nature of the service?
>
> **Q.** How can the right balance be reached between providing assurance and letting people make their own choices?

PDCN provides a joint response to all questions below.

PDCN supports the introduction of a provider registration system to consider credibility and suitability of providers across all levels of support. Current arrangements lack guidance and mechanisms in place to consider diversity of providers and the changing landscape of the sector.

PDCN supports consistency of provider registration across all levels of risk and types of services provided. If a proper check is not carried out, how is the risk in provision of personal care identified? Checks are crucial in minimising abuse, neglect and harm.

Poorly trained staff, people with criminal records and people not providing adequate care and support to the person, all pose significant risks of abuse and harm. For example, the 2009 *Shut Out Report* discusses the risks of suffering physical and mental health problems if adequate supports are not in place to enable them or their carers to effectively function[14]. Support workers who work alone with participants also pose a significant risk if not checked.

The *Inquiry into Abuse and Neglect of People with Disability* (2015) held in Western Australia, recounted numerous cases of people with disability being raped, neglected and humiliated by people entrusted to care for them in group homes, mental health centres and aged care homes[15]. This goes undetected or unreported, because victims either could not communicate what happened or their word is not trusted. This shows lack of accountability, and critically calls for consistent provider checks to be introduced.

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[14] Australian Government (2009) *Shut Out Report: The experiences of people with disabilities and their families in Australia*, A National Disability Strategy Consultation Report, Prepared by the National People with Disabilities and Carer Council, p.45.

[15] Nicholas Perpitch (2015) *People with disabilities raped, beaten, neglected while in care, hearing told*, ABC News, 10 April 2015, accessed at: http://www.abc.net.au/news/2015-04-10/disabilty-hearings-in-perth-report-rape-neglect/6384308

Recommendation:

11. **Make provider registration procedures consistent across all levels of risks and types of service provision, including self-managed clients.**

12. **Introduce checks to address the safety of participants who are directly supported regardless of context.**

Comment: Handling Complaints

> *Q.* How important is it to have an NDIS complaints system that is independent from providers of supports?
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> *Q.* Should an NDIS complaints system apply only to disability-related supports funded by the NDIS, to all funded supports, or to all disability services regardless of whether they are funded by the NDIS?
>
> *Q.* What powers should a complaints body have?
>
> *Q.* Should there be community visitor schemes in the NDIS and, if so, what should their role be?

PDCN will provide a joint response to all questions below.

PDCN agrees a complaints mechanism needs to be introduced, but recommend one be created with independent oversight. It should be independent of the NDIA and be able to oversee actions of agencies, and investigate and respond to allegations, without internal input or influence from the agency.

An independent complaints body will have the ability and capacity to understand the nature and extent of complaints from participants and providers alike, and will allow for critical and swift action to be taken in responding to complaints. PDCN supports the NSW's Ombudsman's comment that this function should be done in partnership with participants, services, and their families[16] .

PDCN recommends that the independent complaints system apply to all services regardless of funding, allowing for the complaints mechanisms to be more consistent, transparent and credible.

An independent complaints system is an incredibly important safeguard. It minimises conflict of interest, ensures transparency and accountability from all involved in service provision, including the NDIA. When significant issues that affect the safety and wellbeing of participants arise, it could independently evaluate the provider

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[16] NSW Ombudsman (2014) Media Release - Media release disability reportable incidents November 2014

environment to determine the extent of how participants exercise choice and control. It could also deal with complaints that cannot be resolved between provider and participant. This increases the credibility and power of the system, in exercising decision making authority to protect the wellbeing of participants and to foster their decision making capacity.

Some participants may face particular challenges in reporting complaints, for example those with cognitive disability, or where their disability affects their communication. An independent complaints function would provide additional safeguards in providing advocacy support in communicating and resolving issues, and ensuring that a person's statements are seen as credible.

PDCN is aware from information received from Advocacy for Inclusion, where people with disability have faced numerous issues with service providers transitioning to the NDIS, to name a few:

- People with significant communication barriers being spoken for by service providers or carers, and not being given the chance to outline their own choices;
- Service providers giving consumers a printed list of services they currently use to 'tell the NDIS this is what you will need'[17]

In situations where a service provider is overbearing, an independent body to make complaints is crucial. An overarching complaints body could then monitor these complaints and take action where necessary if this is a recurring issue.

The reports of abuse identified in the Four Corners documentary of Yoralla also identifies the issue where complaints are redressed through organisational policy, which may in fact be cases for the justice system. An independent oversights body would ensure redress occurs in the appropriate system.

The NDIA Factsheet, Making Complaints, has the advocacy safeguard option listed under the Complaints and Your Rights section. PDCN recommend this option also be introduced in the role of an independent complaints body as well and also have this information disseminated more widely, so people are aware of the options available to make complaints .

Recommendation:

13. **Introduce an Independent Complaints Oversight Body**

14. **Introduce additional complaints safeguards for vulnerable participants**

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[17] Advocacy for Inclusion (2015). More Independent NDIS Support Needed Up Front (LinkedIn article)

Comment: Ensuring Staff are Safe to Work With

> *Q.* Who should make the decision about whether employees are safe to work with people with disability?
>
> *Q.* How much information about a person's history is required to ensure they are safe to work with people with disability?
>
> *Q.* Of the options described above, which option, or combination of options, do you prefer?

PDCN will provide a joint response to all questions below.

PDCN supports a combination of options regarding the decision making process on whether employees are safe to work with.

For participants using service providers or brokers to manage their funding, PDCN supports implementation of Option 2 (Require referee checks for all roles and police checks for certain employee roles) and Option 3 (Working With Vulnerable People Clearances) as suggested in the Consultation Paper[18]; where the employee works directly with the participant with a disability. It is critical to ensure staff working directly with the participant are safe to do so. Without a check, the participant is exposed to vulnerability and harm. Checks act as a legal and personal safeguard. It is important (as stated under the *NSW Disability Inclusion Act 2014*) that employees undergo police and reference checks[19]. Mandating a working with vulnerable people check for employees who have direct access to people with disabilities in addition to police/reference checks, would add an additional layer of safeguarding.

Additionally, where a police check did indicate an issue that was not a 'prescribed offence', the employer could use their discretion to decide whether to employ the person, based on the relevance of the offence. Equally, Option 4 a 'barred person's list', would not allow for the flexibility for employers to decide on individual situations.

Option 1 represents a reduction in requirements, so would not be appropriate.

Any type of information obtained about the employee's history is vital in making an informed decision about whether the employee is an appropriate choice. Countless employers have encountered incorrect information on an employee's resume or record, which increases the risk of vulnerability or harm to participant. Despite this, a number of employers still fail to carry out checks, which some attribute to a lack of time

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[18] 18 NDIS (2015) Consultation Paper: *Proposal for a National Disability Insurance Scheme Quality and Safeguarding Framework*, February 2015, p.61-62.

[19] NSW Government (2014) *Disability Inclusion Act*

or resources, checks should be mandatory and should not be negated due to recruitment costs[20].

Self-managed participants should also exercise full decision making autonomy over whether staff are safe to work with (with support if required from independent advocacy services).

Considerations however need to be made in terms of costs for checks and how this will affect a person's individual funding package. PDCN has spoken to individuals who are self-managing their support. As an employer of their support staff, they are responsible for ensuring staff are safe to work with by paying for relevant checks. Issues have been reported during times where a turnover of staff has occurred. Safety checks are to be repeated for new staff at the cost of the individual, which can cause financial hardship for the person and affect the funded support of their package[21].

Recommendation:

15. **Joint implementation of Option 2 (Require referee checks for all roles and police checks for certain employee roles) and Option 3 (Working With Vulnerable People Clearances) as stated in the Consultation Paper.**

16. **Make relevant safety checks of staff mandatory for services who support people with disability**

17. **Consider how costs associated with checks can affect individuals who are self managing and directing support. What assistance is available to support those who may experience financial hardship where checks are regularly repeated.**

Comment: Restrictive Practice

Q. Who should decide when restrictive practices can be used?

Q. What processes or systems might be needed to ensure decisions to use restrictive practices in a behaviour support plan are right for the person concerned?

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[20] Lauren Connors (2014) *Cost of a Bad Hire vs. Cost of a Background Check*, accessed via IQ Blog Compliance, Criminal Records, Litigation, Resume Verifications: http://www.employeescreen.com/iqblog/cost-of-a-bad-hire-vs-cost-of-a-background-check ; https://www.linkedin.com/groups/Cost-Bad-Hire-vs-Cost-2933968.S.5932876840497606656

[21] PDCN (2015). Telephone statistics

PDCN believe that restrictive practices should only be used as a last resort. Decisions regarding use of restrictive practices should only be made by trained individuals who have knowledge of the individual, and who also have expertise in positive behaviour support, and only where more positive alternatives have not been successful.

It is important to note the use of restrictive practices may reflect a failure in the service system where the nature and function of an individual's behaviour is not understood. Behaviours are often the result of and are triggered by a number of contributing factors including health issues, environmental factors, or social contexts. These behaviours can further be exacerbated where restrictive practices are used which do not address the trigger of the behaviour.

Considerations around restrictive practices and the promotion of positive behaviour supports should not be isolated to disability service systems. The recent media reports where a child with autism was locked in a cage in a classroom in a public primary school in Canberra, identifies the need to have frameworks across all systems, to avoid this inhumane treatment occurring again[22]. Whilst it is unknown if the student in this report had an Individual Education Plan, or a behaviour support plan, this example identifies the need for positive behaviour plans to be in place, up to date, and ensure people who are working with a person are aware of positive strategies they contain.

With the transition to the NDIS individuals with disability will have the opportunity to engage in more mainstream activities and contexts outside of the disability sector. It is therefore crucial that frameworks, education, training and awareness of the use of restrictive practices is available in different contexts (especially where a person is not accompanied by any support person.)

Where behaviour support plans are in place, it is important these are reviewed regularly and in consultation with the individual, their family or guardian/person responsible. Person centred practices should be a key guiding principle in eliminating restrictive practices, where considerations are focused on the individual's wellbeing, avoidance of triggers of behaviour and identify positive alternatives suitable to the individual[23].

From a management perspective regular reporting provides opportunity for what is referred to as 'continuous improvement' where a quality review process is employed

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[22] Canberra Time (2015). *Special Needs Child Locked in Cage.* Retrieved from: http://www.canberratimes.com.au/news/special-needs-child-locked-in-cage-20150402-1mdukl.html#ixzz3WlhEPREC

[23] PDCN (2013) *Reducing the use of Restrictive Practices in the Disability Service Sector*, Submission for the Department of Families, Housing, Community Services and Indigenous Affairs, p.4

to refine and re-evaluate what the organisation is doing and what adjustments may be required to achieve standards[24].

Additional comment:

PDCN disagrees with the Consultation Paper's use of the word 'challenging behaviour' as the term itself pre-empts confusion on what constitutes as challenging behaviour. It could also imply fault of the individual. PDCN suggest the Framework adopt more inclusive terms that relate to behaviours that put the participant at risk of injury to themselves or others[25]. For example, the PDCN Submission on Restrictive Practices (2013) proposed 'behaviour of concern' as an alternative term to use[26].

Recommendations:

18. **Ensure frameworks identify the use of restrictive practices be used as a last resort and decisions made by trained persons who have knowledge of the individual, and who also have expertise in positive behaviour support, and only where more positive alternatives have not been successful.**

19. **Make considerations outside of the disability sector of how awareness and education relating to positive behaviour strategies can be provided to mainstream systems.**

20. **Include policies to ensure regular updates of individual behaviour support plans are developed with the individual, their family or guardian/person responsible, ensuring the person's needs are the focus at all times.**

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[24] Lassiter, V, (2007) The role of process improvement in the non profit organisation

[25] Ibid, p.3.

[26] PDCN (2013) *Reducing the use of Restrictive Practices in the Disability Service Sector*, Submission for the Department of Families, Housing, Community Services and Indigenous Affairs, p.3.