



**Physical Disability Council of NSW**  
Ordinary People Ordinary Lives

Submission to the Ageing and Disability Commission

Disability Advocacy Review Issues 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. We are also a disabled persons representative organisation (DPO), with people with disability making up the majority of our board, staff and our membership. This includes people with a wide range of physical disabilities, from young children and their representatives to aged people, who are from varying 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 can 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 to the Ageing and Disability Commission on the Disability Advocacy Review Issues Paper. As a peak body representing people with physical disability, PDCN will not answer each individual question, rather respond to the key areas for discussion as outlined in the issues paper.

As the peak body for people with physical disability, PDCN provide systemic advocacy, expertise and advice to our members and stakeholders, taking their collective issues and concerns to government or other relevant industry bodies in order to work collaboratively to improve their human rights, participation and inclusion in all parts of NSW society. We also do this through the preparation of written submissions and reports, providing evidence at government inquiries, and provide expert advice on numerous NSW government, corporate, independent and not for profit advisory committees and boards (around 25 at current count).

Our vision is for a society where our human rights are protected and upheld, equality of opportunity is assured, and full participation is a reality. PDCN also provides a range of free services to our members, or any others that request it - from dealing with member enquiries and subsequent information provision, or onward referral, to education and capacity building workshops and programs, to proactively partnering with government and local community organisations to address opportunities for inclusive projects that can bring about full inclusion in NSW society for people with physical disability.

PDCN suggests that, when undertaking a review of disability advocacy services, the principles upon which any new system of advocacy is enshrined should uphold a person's human rights, and align with the United Nations Convention on the Rights of People with Disabilities (UNCRPD), to which Australia is a signatory, along with meet the NSW government's obligations to the National Disability Strategy and Agreement, the Disability Discrimination Act, and NSW Disability Inclusion Act 2014.

PDCN call on the NSW government to roll over current funding arrangements for an additional two years to provide adequate time for individual organisations to administer any changes, and to ensure continuity of services remains for the people with disability we represent and assist. This takes into account the many areas under consideration within this review that may affect the way advocacy is delivered post June 2020 and the current time frame available to consider the outcomes proposed, make decisions on any changes to current systems, and implement these changes effectively – whilst also ensuring continuity of support for people with disability.

We believe that the time factor required to manage all change processes for our organisation would extend beyond the current NSW advocacy funding arrangements (end June 2020).

### **Principles that could be applied when considering a review of disability advocacy in NSW**

The issues paper outlines a number of principles that can be applied to this review, and PDCN would like to note that it agrees in part with these principles, however it would also recommend including or re-wording them as follows -

- **Protecting, upholding and promoting the rights of people with disability** enabling the NSW government to meet its obligations under a human rights framework and associated state and federal legislation, ensuring people with disability have a voice, choice and control over their lives.
- **Enabling people with disability to self determine their rights and have their own voice, choice and control over their lives.**
- **Ensuring people with disability can access appropriate, specialist, independent, and locally available disability advocacy supports and services.** Valuing the expertise, relationships and experience of local disability advocacy services and the importance of continuity to the communities they serve, by embedding disability advocacy services in local communities.
- **Enabling people with disability take part in public debate and government decision-making that affects them.**
- **Recognising the critical role that systemic advocacy plays in identifying system change needed to the laws, policies and processes that uphold and protect the rights and voice, choice and control of people with disability.** Systemic advocacy

plays a critical role in addressing ‘overarching’ issues, or discriminatory practices common for all people with disability (and often other cohorts by default) – and can deal with these once overall, thereby reducing the need for ongoing individual advocacy.

- **Ensuring disability advocacy is genuinely independent of traditional service provision, and no perceived or actual conflict of interest exists.**
- **Disability advocacy organisations should be fully resourced, long-term, to deliver responsive, timely, and culturally or disability specific appropriate supports and services.**
- **Disability advocacy organisations and Government work together to define, demonstrate and share the outcomes and impacts of disability advocacy.**

PDCN would also recommend the term ‘best interest’ be changed to “voice, choice and control”. We suggest making this change as “best interest” is not always reflective of what the individual wants. People with disability should be involved in all decisions regarding their life – and where necessary, supported to do so. Guardians, for example, may make decisions in the person’s “best interest” however this may not be the same as what the person themselves wishes. Individuals have the right to choose to do something that may not be in their ‘best interests’ but have decided that the risk entailed in a different choice is reasonable for them to assume (dignity of risk).

### **Patterns of need for people with disability in NSW**

The advocacy needs of people with disability are diverse, and as such there needs to be as diverse a range of services as possible available to them to protect their rights and achieve full inclusion and participation in society. Cohorts that may be affected by intersectionality issues (such as disability and being of CALD, LGBTQI or indigenous backgrounds) or a specific disability type (physical, intellectual, psychosocial) or even disease type (cerebral palsy, spinal cord injury, muscular dystrophy etc.) can all benefit greatly from specialist, expert advocacy. Additionally, having locally based organisations, particularly ensuring reach into rural and regional areas, is just as imperative to supporting an individual’s advocacy needs.

Whether we like it or not, much of PDCN’s work over the past 5 years has been focused on supporting our members, and the wider disability community, through the roll out of the NDIS. In 2015/16, as people began to become aware of the scheme, calls requesting information or assistance to the NDIS were the second highest of all PDCN’s enquiries. In the 2016-17 year enquiries about the NDIS, or to attend workshops we deliver to assist people in understanding and accessing the NDIS jumped to 46% of all requests. In 2017-18, 2018-19 and 2019-20 36%, 37% and 33% (respectively) of all enquiries are still related to the NDIS and our NDIS workshops.

These figures clearly indicate that the current advocacy needs for many people revolve around an emerging sector and have in fact, at present, added to both their advocacy needs and PDCN’s own workload – as other systemic work has not decreased alongside of these new requests.

However, only 10% of people with disability are eligible for a NDIS package, leaving more than 1.2 million people with disability in NSW reliant upon advocacy and other supports to help them navigate the changing disability and mainstream service landscapes. It is also important to note that Australia has an ageing population whom are a critical cohort to consider, as people over 65 are not eligible for the NDIS, yet experience high rates of disability. This cohort relies on advocacy to help them navigate either an inadequate aged care system, dwindling disability services system and other mainstream supports and will only continue to increase as a population, and are therefore relevant to any discussion on patterns of need.

### **Areas of focus, mechanisms, kinds of advocacy and activities carried out under ‘advocacy’**

Different types of advocacy have different roles to play in addressing discrimination and disadvantage. PDCN agrees with the broad “types” of advocacy outlined in the issues paper, however, would prefer the term “individual advocacy” be used over “supported advocacy”, as this term is not commonly used in Australia. We would also suggest that this list is not complete, that the different types described are not mutually exclusive, and that it may hinder our ability to do effective work if ‘siloes’ into one particular stream.

PDCN would recommend including citizen advocacy and family advocacy to the advocacy focus areas. This would be in line with the National Disability Advocacy Program (NDAP) funded models of advocacy, which includes systemic, self, individual, legal, citizen and family.<sup>1</sup>

PDCN would also suggest splitting systemic advocacy and representation, as these can be two very different subsets of advocacy. Whilst it is always the case that a representative organisation (where people with disability represent their own rights, issues and needs – such as through DPO’s) will also deliver systemic advocacy, a systemic advocacy organisation may deliver advocacy without any representative structure whatsoever.

When reviewing the activities matrix, PDCN recommends adding “conduit between agencies” to this, as PDCN often works in collaboration with other, non-disability organisations, to connect people with disability to services or information. ‘Provision of information’ and ‘referral’ are also activities that could be added. The matrix of activities in the issues paper is useful in broadly defining what organisations do, but PDCN does not want to see a framework so tight that other important activities aren’t considered if not specified within the matrix – and therefore may not be funded.

For example, PDCN is a systemic advocacy organisation, however it also provides an information line and referral service for its members (and the general public). Although PDCN is not a formal ‘information service’, we still receive a number of enquiries via phone or email daily, and would continue to do so no matter the future funding arrangements, that we need to respond to (we can’t NOT pick up the phone when it rings!) and act on the request of the caller. Our members trust us

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<sup>1</sup> NDAP Operational Guidelines  
[https://www.dss.gov.au/sites/default/files/documents/03\\_2018/ndap\\_operational\\_guidelines\\_february\\_2018.pdf](https://www.dss.gov.au/sites/default/files/documents/03_2018/ndap_operational_guidelines_february_2018.pdf)

and value our expertise and will use PDCN as a first point of contact for many varied issues, some of which we can manage inhouse, and some of which we would in turn refer onwards to the relevant organisation or body.

This in turn informs the systemic work we do – it's a useful way of collecting data on what the issues people with disability are regularly confronted by and in turn prioritises the focus areas of our work. We believe there needs to be acknowledgement that some of what PDCN, and most likely other advocacy organisations, do is adhoc information and referral, which takes up time and resources, and that there needs to be recognition of this work in any future funding agreements.

PDCN believes that for consistency and to assist those organisations that are funded by both Commonwealth and State governments, that NSW's disability advocacy framework should align with frameworks in other states, territories and nationally, where this alignment ensures best practice. Furthermore, PDCN believes this review provides an opportunity for NSW to become a leader in designing a best practice framework for disability advocacy, as currently having researched the other options already in place, there does not seem to be a single comprehensively designed structure that meets all requirements, and PDCN would welcome the opportunity to work with government to co-design a revised framework.

### **Achieving and reporting outcomes through disability advocacy**

PDCN recognises the importance of measuring outcomes (as opposed to outputs) and believes reporting against a framework is the best approach to measuring the impact of advocacy services. PDCN also believes outcomes measurement as a form of data collection is a sound way to build a profile of disability issues and trends. However, we suggest that doing so should not be too onerous or time consuming for organisations, and recommend reporting occur every six or 12 months, so as not to place any unnecessary burden on services.

In addition, there should be recognition of the differences in capturing outcomes for individual and systemic advocacy. It is generally easier for individual advocacy organisations to measure their outcomes than it is for systemic organisations. Individual advocacy organisations can report the number of people assisted, and also what the individual outcomes achieved were for those people (noting they may not always be the outcome hoped for) usually within a relative short period.

Systemic advocacy outcomes can take years to achieve and are often reliant on many varied stakeholders (ie: decision makers) agreeing on a position in order to achieve the outcome desired. For example, PDCN advocated for the Sydney Harbour Bridge 'Step Free' Access Project which involved working with the NSW Roads and Maritime Services, Sydney Harbour Foreshore Authority, City of Sydney, North Sydney Council, project management and many other stakeholders to bring about lift access to the pedestrian walkway of the bridge. The lifts were opened in early 2019 after a process that exceeded 10 years. While the number of meetings, development of partnerships, user testing and other planning activities involved can be reported each year, the actual outcome of the advocacy work – the opening of the lifts – could only be reported once the lifts had been installed.

PDCN suggests the sector and government work together to achieve an outcomes reporting framework that appropriately measures the work of both systemic and individual advocacy organisations.

A nationally consistent framework, for example NDAP's, would be useful in ensuring consistency, collating results and understanding the national disability landscape, however PDCN would point out that this program is currently under review, and the indicators referenced in the issues paper<sup>2</sup> do not provide an outcomes framework, rather a set of practice standards for disability services, providing guidelines on how they undertake their work, and the required evidence needed to support those practices. We note that Standard 3 (Individual Outcomes) within this document does talk to some outcomes evidence, however this is mixed with evidence of plans, policies and procedures, staff training requirements and promotional materials, which would not be relevant in an outcomes framework. Hence PDCN does not consider it appropriate to use this as a basis for an outcomes framework for NSW.

PDCN believes an overarching resource system or body, designed to collect information on issues and cohorts, and provide resourcing and support to the sector would be the best approach to developing an outcomes reporting framework. This body would be able to collect and collate all individual organisation's data and use it to inform advocacy more broadly. While PDCN does not believe there is one perfect model in Australia, the Victorian Disability Advocacy Program, including the Disability Advocacy Resource Unit (DARU) and Self Advocacy Resource Unit (SARU), may provide a good starting point for developing an overarching resource and reporting system.

Given the current role of the NSW Disability Advocacy Alliance in bringing together more than half of the currently funded TAPS organisations, and the sector collaboration built through this mechanism, consideration could be given and exploration undertaken into how this entity could be funded to play a part in providing a central hub for resourcing, training, assisting with outcomes management, information sharing and identifying systemic trends, and supporting the sector in its advocacy work moving forward.

### **Factors for informing a new system of funded advocacy in NSW**

There are a number of factors that should guide the development of a new system for the provision of funded advocacy services in NSW. These are outlined below.

**Independence is critical.** As the issues paper raises, there is debate around whether disability advocacy services should be independent from the disability support system, and even

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<sup>2</sup> *National Standards for Disability Services Indicators of Practice and Examples of Evidence for NDAP agencies*  
<https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/national-disability-advocacy-program/national-standards-for-disability-services-indicators-of-practice-and-examples-of-evidence-for-ndap-agencies>

Information Linkages and Capacity building funding (ILC) provided by NDIA funded services, so they can freely perform their functions. PDCN strongly believes that advocacy services should be separate from traditional, direct service provision. This would avoid any conflicts of interest that may arise when an organisation is providing both advocacy and direct paid services.

PDCN believes that the role of support coordinator and plan manager may help produce better outcomes and inform the advocacy process particularly where issues may be highlighted with individual service providers or services, however we acknowledges the need to ensure complete separation of advocacy services from support coordination and plan management. We also note that traditional services such as day programs, personal care, accommodation services, therapies, etc. should not be provided by an advocacy organisation.

ILC funding has no bearing here, as it does not fund individual or systemic advocacy. More importantly, in line with the issue of independence, the ILC does not fund individuals or services. ILC grants are specifically for capacity building projects that provide opportunities for people with disability, the mainstream system and community (such as education, skills development, peer connection and information provision). The ILC should, over the longer term, compliment the work that advocacy undertakes in terms of building community participation and inclusion. However, there is currently great concern over the capacity of the ILC to do this fully and effectively due to the current level of funding, inconsistent delivery across states and territories, the varied cohorts of disability and in the very nature of the short term project based application of funds.

**A human rights framework.** Any system of funded advocacy services should have the voice, choice and control of people with disability at the forefront, and in its design.

**Recognising the needs of different cohorts and those experiencing double disadvantage including CALD, ATSI and LGBTIQ communities, and those in rural, remote or regional areas.** These communities require local, specialised services and any funding model should ensure that the knowledge, expertise and experience of local services is valued and retained so they can continue to provide services to the people in their communities who have come to rely on them.

**Recognising the importance of DPOs and their role in self representation for people with disability.** DPOs are organisations staffed by and for people with disability and they are essential in ensuring the needs of people with disability are represented, are advocating for change and are raising awareness. DPOs are unique to the advocacy space for their ability to have the voice of people with disability at the forefront and involved in every step of the process.

**A funding model that is based on actual need.** The current (or interim) model provides block, rationed funding that does little to address the actual level of need, resourcing or sector development, leaving significant gaps in the provision of services, and long waiting lists for many. Adequate funding for systemic advocacy undertaken by peak organisations is essential. Within the current funding arrangements there is considerable imbalance both within and across cohorts and this too should be resolved to ensure equitable access to all types of advocacy for all disability



groups. While individuals will continue to need support when they are experiencing barriers to service provision or inclusion, discrimination or an abuse of their rights, advocacy funding allows these issues to be addressed systemically, which is both cost effective and relieves individuals from the constant need to advocate for those rights – allowing them to live an ‘ordinary life’, and reduce societal barriers once and for all.

### **What resources are required for effective and efficient system provision of funded advocacy services in NSW?**

NSW is now in a unique position to be able to look at disability advocacy service frameworks around Australia – and the world – and develop a system that is well resourced, well administered and ensures all people with disability have access to the supports they need, when they need it.

However, the NSW disability advocacy, information and representation sector is currently significantly underfunded and under-resourced. Any new system, if it is to be effective and maximise outcomes for people with disability requires an increase in its workforce, regular staff training and skills development and the financial resources to meet the needs of people with disability in NSW.

Current workloads, increased demand on our services and incredibly tight staff levels mean that PDCN is not able to address many of our member identified systemic priorities nor meet the many constant requests for expert advice coming from government themselves and other worthy stakeholders. As mentioned previously in this paper, this has been particularly affected by the poor roll out of the NDIS, and while we do not wish to turn this into a discussion on the flaws of the NDIS, it is relevant to the question of resourcing - chronic under resourcing means that when a reform as significant as the NDIS occurs, other areas get pushed aside because we simply do not have the capacity to do everything. Even as we move away from responding to needs arising from the roll out of the NDIS, PDCN still finds we must be selective in what we prioritise in terms of our systemic advocacy, because we simply do not have the capacity to respond to every request or issue that comes through our door.

As a peak representative organisation, PDCN is relatively small compared to other peak advocacy bodies, however we believe we ‘punch above our weight’ in the amount of work we do, and in the positive contribution we make to inclusive change. In 2018-2019 alone, PDCN participated in 104 representative meetings, 30 one-off consultations, delivered 19 written submissions and sat on 24 advisory boards or committees, along with providing assistance to thousands of people with disability (through enquiries/referral, workshops and capacity building, information provision via a variety of media, expos, consultations and other platforms) always representing the needs of people with physical disability – all of this with a funded staff of 2.5 full time equivalent employees!

At the same time, we were unable to accept offers to provide expert advice on numerous department and industry working groups and consultations, missed giving feedback via submissions to other relevant inquiries that affect the lives of people with physical disability, nor actively address many of the important issues that negatively impact on the participation and

inclusion of our members, people with physical disability in NSW community – such as health interface concerns, the serious lack of accessible or affordable housing, high rates of underemployment, or the inability to access local shops and services due to physical barriers, to name but a few.

Additionally, PDCN, along with other disability advocacy organisations, lacks capacity building resources. The ability to provide time and funding for sufficient ongoing training and development affects staff retention and the sustainability of an organisation. The sector as a whole would benefit greatly from resources that supported capacity building, including staff training and development, outcomes collection training and software support, and time for sector wide collaboration.

Also addressed earlier in our submission, PDCN believes that the sector would benefit from an advocacy body that is able to support the sector through resource development and provision, sector training, building sector collaboration, acting as a point of collection, coordination and analysis of outcomes data and in identifying systemic or other issues, similar to Victoria's DARU. It is essential that this body be disability advocacy specific, as social service peak bodies simply do not have the resources, expert knowledge or capacity to support disability advocacy in this way. This body could sit under, or alongside, a disability peak body, however it would need to be separately funded to ensure it could deliver resources to the sector.

### **Who is responsible for funding advocacy?**

PDCN believes it is vital that the disability advocacy sector is adequately funded in the long term to ensure the rights and voice, choice and control of people with disability remain at the forefront of every decision and full inclusion in NSW society is achieved. We also believe that both Commonwealth and States have a role to play in ensuring all people with disability have equitable access to the supports necessary to be fully included in Australian society.

However, the NSW advocacy sector, particularly those organisations that work at the state level only, should be funded by the NSW Government, as the issues we work to address are, on the whole, state based. Additionally, the relevant laws and services to which these issues pertain are the responsibility of NSW government who are obliged under the National Disability Strategy and Agreement, the Disability Discrimination Act, NSW Disability Act and Disability Inclusion Action Plans to ensure the rights and needs of people with disability are recognised and realised.

Where there is funding from both state and federal government, there needs to be clarity around what the process for funding is and what each level of government will fund. The NDAP is a good starting point however it is inconsistent in its application, and nowhere near sufficient to meet both State and Commonwealth advocacy requirements, nor is it appropriate that it should do so.

The Productivity Commission, in its review of the National Disability Agreement, found that there was no clarity in the Agreement over who will fund certain disability services, including advocacy,

and that this was something that needed to be included in the new Agreement.<sup>3</sup> This report recognised that while some states have committed to funding during the roll out of the NDIS, they have not given any indication of whether or not they will fund advocacy in the long term, preferring to ‘wait and see’ what the NDIS and NDAP will fund – to the detriment of people with disability.<sup>4</sup> PDCN believes that this needs to be urgently addressed in order to end the circular arguments between the federal and state governments as to where the responsibility for funding advocacy lies.

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<sup>3</sup> Productivity Commission 2019, *Review of National Disability Agreement*, <https://www.pc.gov.au/inquiries/completed/disability-agreement/report/disability-agreement.pdf>

<sup>4</sup> *ibid*