#### INFORMATION, NEWS AND SUPPORT

# PDCN Live





Serena Ovens, Executive Officer

Welcome to the final PDCN Live newsletter for 2018.

As yet another year rolls to an end and we get ready to close the doors for a short break, we thought we'd use this edition to give you a look back at some of the work undertaken throughout the year -

much of which is not seen or visible, and sometimes takes years to achieve - but importantly progresses much needed law and policy change in our quest for equality of access and citizenship.

Personally, I want to take this opportunity to thank all our members and stakeholders for taking such an active part in PDCN's lobbying for change - this year was a busy one with the Sydney Harbour Bridge call to action, then the #StandByMe campaign - but having people with disability out on the ground publicly demanding that change occurs made all the difference. As many of you are aware, we are still busy working on the #StandByMe campaign in the lead up to the election - to secure a long-term funding commitment - and we'd love to have you continue to show your support as we undertake even more public actions in the new year. Stay tuned for further ways you can help!

Additionally, the team here at PDCN deserves a huge vote of thanks. With only five of us, sometimes the amount of work to do and change still to be achieved seems overwhelming, but time and again they step up and pull together to get things done, and I'll take this chance to thank them publicly for the support and commitment they too give to achieving PDCN's vision.

From myself and all the PDCN team, have a safe and happy Christmas, and a prosperous New Year!

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# Sydney Harbour Bridge is #EverybodysBridge at Last!



After more than 10 years of advocacy, planning and much consultation with the many other stakeholders involved, PDCN were thrilled to join the celebrations marking the opening of the southern and northern Sydney Harbour Bridge lifts on Wednesday 17 October and Tuesday 23 October this year.

After standing beside the then Minister for Roads Duncan Gay and Minister for Disability John Ajaka on 16 July 2016 to announce that funding had been secured for the lift access project, things took a turn for the worse when a year to the day thereafter the government took the project off the funding schedule and it looked like step-free access to the iconic landmark might be lost.

However, thanks to you our members, along with many concerned members of the public and other like-minded organisations, the fight to retain funding was successful through our quickly coordinated #EverybodysBridge campaign, and we thank the NSW Government for hearing our concerns and ensuring the project made it to completion.

At the official opening ceremony, PDCN's Serena Ovens and President Chris Sparks joined NSW Minister for Roads and Maritime Services Melinda Pavey and North Shore MP Felicity Wilson as they officially opened the new lift on the southern end of the bridge. Plenty of media coverage was generated, particularly in light of the Invictus Games and the Royals' visit to Australia.

We were extremely pleased to be a part of the historic moment!

Thank you to all the people involved with making the project possible: to the NSW Government and all political parties who supported this accessibility project, City of Sydney and North Sydney local councils, the project team at Roads and Maritime Services, the John Holland construction team and all others who had a hand in making it happen.

The newly accessible bridge is a practical and highly symbolic reminder of the vital role that disability advocacy plays in a state where disability advocacy funding is under threat.

## Julia Mansour Board Member Profile



### What attracted you to the position on the PDCN board?

As a lawyer, I was keen to volunteer and use my skills in a community context. I first came across PDCN because of the strong partnership it has with my old employer, PIAC (Public Interest Advocacy Centre), and I knew from that how valuable the work it does is in advocating for the community. When the Board position was advertised, I jumped at the opportunity!

# Where do you feel you can add the most value to PDCN in your role as a Board member?

I believe I can contribute to the Board's thinking on all kinds of legal issues

from major contracts, to governance and policy issues, to employment structures.

## What do you see as the most important issues for PDCN/or the disability sector currently?

I think there are a lot of complicated issues for PDCN and its members that arise out of the transition to the NDIS - both challenges to funding for advocacy organisations, and challenges for individuals in accessing services they need to live ordinary lives.

#### Tell us about other things that interest you outside of the disability sector.

I'm a lover of literature and languages, as well as traveling and all outdoor activities. I'm currently trying to learn Auslan, though it's a very slow process!

# 2018 The Year in Photos





### **NSW Parliamentary Inquiry into the NDIS**

In June the NSW Government established an inquiry to report on the provision of disability services and the implementation of the NDIS in NSW, and PDCN Executive Officer Serena Ovens and Policy Officer Ellen Small were invited to appear at the public hearing on 2 October. This was an opportunity to raise our concerns about service gaps for people with disability created by the rollout of the NDIS and to elaborate on issues we identified in our written submission. The evidence we presented at the inquiry was directly informed by the experiences of our members and service users.

A key area of concern for PDCN is a lack of choice and control for participants due to the rushed pace of the NDIS rollout. We have seen inconsistency in NDIS plans and a lack of support for participants to implement their plans. The funding model used by the NDIS will also see a greater casualisation of the disability workforce and may compromise the level of care received by participants.

PDCN also spoke about the gap that has appeared for individuals who are ineligible for the NDIS who previously received low-level support through the discontinued Community Care and Support Program. PDCN wants the state government to commit to ensuring these individuals continue to receive essential disability supports. PDCN is also anxious about the closure of ADHC, which has left people with disability without a provider of last resort.

In addition, issues arising at the interface between the health system and the NDIS were discussed, and PDCN would like an urgent resolution of the disputes between NSW Health and the NDIA over the funding responsibility for community nursing services such as catheter changes for NDIS participants.

PDCN also raised the issue of continued funding for disability advocacy services in NSW, as all people with disability, particularly those without access to NDIS packages, will be far worse off without continued access to support, information and advocacy services.

On 6 December, just prior to going to print the Government released their report on the inquiry findings. The report validated many of the concerns PDCN raised, and includes 23 recommendations, many calling on the NSW Government to more actively pursue NDIS related issues through its role on the COAG Disability Reform Council. We are also delighted to note that key recommendations include ongoing funding of disability advocacy organisation such as ours, and investment in other services and supports particularly for those not eligible for the NDIS.

If you would like to read the final report, or submissions or transcripts related to the inquiry, please visit the NSW Parliament website here <a href="https://www.parliament.nsw.gov.au/committees/inquiries/Pages/inquiry-details.aspx?pk=2496#">www.parliament.nsw.gov.au/committees/inquiries/Pages/inquiry-details.aspx?pk=2496#</a>

### **Stand By Me Campaign Relaunch**



Following a short reprieve campaigning on the imminent loss of our disability advocacy funding, the NSW Disability Advocacy Alliance used the NSW Parliamentary Inquiry into the Implementation of the NDIS in NSW to relaunch our campaign calling for long-term, sustained funding of our vital, and often life-saving, services and supports.

Prior to giving evidence at the second day of hearings on October 2nd we called a press briefing in Martin Place and launched our Gaps Report - a report highlighting the crucial work disability advocacy, information and peak representative groups undertake, and the current, and soon to be significantly greater gaps defunding the sector will cause. The briefing saw us speak to numerous media outlets, including a live interview on Sky News, once again bringing our campaign to the attention of the general public.

In the lead up to the NSW election we are calling on all PDCN members and supporters to assist us in doing your bit - as people with disability your voice is the most important in this campaign. Please help us by emailing the Premier and telling her that you want her to commit to ongoing funding; or better still, pay a visit to your local MP and let them know how important advocacy organisations like ours is to you, and that you'll be voting for the candidate that supports the funding call. If you are unsure of how to do this, call the PDCN office and we will help you, and even come with you if you would like us to!

Visit <u>standbyme.org.au</u> to find more tools to help you easily email the Premier, or to find your local MP and talk about advocacy funding when you meet with them.

Lastly, keep an eye out for our regular e-news, as in the coming months we'll look to do some simple actions, like tying 'Stand By Me' ribbons and posters outside MP offices, rallying locally, doing 'pop up' Stand By Me choirs and other things you can easily be a part of. Let's continue to put the pressure on and make sure Premier Berejiklian and all MPs understand the need for continued advocacy, information and peak representative organisations in bringing about full inclusion for people with disability in NSW and providing you with a voice in the long-term!

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### **Should You Opt Out of My Health Record?**



My Health Record is an online management system for every Australian's health records, intended as a centralised system to store your additional health information and allow different healthcare providers to readily access it. There are some real potential benefits to increasing the efficient communication of patient information across different healthcare providers. However, concerns have been raised about the online security of sensitive health data, who will have access to it, and the overall effect on individual privacy.

A digital My Health Record will automatically be created for you on 31 January 2019, unless you purposely opt out of the system. It's your right to opt out if you wish, but it's important to make an informed decision about whether My Health Record is right for you at this time.

People who are most likely to benefit from having a My Health Record are those with complex health conditions, the elderly, people taking multiple medications, and people who see multiple healthcare providers. Some of the things you may wish to consider when deciding are sensitive health issues or life circumstances, the security settings and privacy controls available within My Health Record, third party access to records, and the protections available for victims of domestic or family violence.

To provide more detail and help you decide whether to opt out or not, Health Consumers NSW have published a helpful summary of key points, setting out the factors you should consider in a straightforward way. You can find this guide at <a href="https://www.hcnsw.org.au/pages/some-factors-to-consider.html">www.hcnsw.org.au/pages/some-factors-to-consider.html</a>.

