



Serena Ovens
Chief Executive Officer

Welcome to the September edition of PDCN Live!

As we continue to navigate a very different landscape than most of us have ever known, I hope that you have been able to find a balance and, where possible, are experiencing the increased access new technologies bring.

PDCN too has pivoted to doing most of our work online – ensuring we can still run our peer groups, workshops and individual support as well as provide the vital information people with disability are looking for. Keep an eye out for upcoming workshops on the website, we'd love to have you join us.

On a positive note, PDCN has ended the 2019-20 financial year in a strong position, with what looks to be a reasonable surplus. In addition, we've managed to achieve, and in many cases surpass, our expected funding outcomes for the year. We'll report in more detail on these at the upcoming Annual General Meeting and in our Annual Report.

Unfortunately, we'll be running our AGM by video conference this year. I'll miss the chance to get together as we usually do and celebrate our success with you all in person. However, on the upside this means all our members can be present, no matter where you live in the state – making the night even more accessible for all. Keep the evening of Tuesday 3 November free and join us virtually!

As ever, we've been busy advocating for change, with a number of key pieces of legislation and strategies up for review. This includes submissions to the Disability Royal Commission

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on emergency preparedness, calling for better levels of universal design within the National Construction Code, and addressing the National Disability Strategy as it is reviewed in readiness for its second iteration in 2021. Our policy officers also gave evidence to the NSW Parliamentary Inquiry into Point to Point Transport – speaking up for greater access and choice in these forms of transport.

But enough from me, read on for the truly interesting stuff!

Serena

Our AGM is Online This Year



As previously mentioned, to remain Covid Safe, we will run our Annual General Meeting by virtual means this Tuesday 3 November.

After testing numerous options, we will do this using Zoom videoconferencing. For any PDCN member who is not familiar with this technology, the PDCN training team can assist with one-on-one training sessions prior to the AGM to assist you to in getting set up and confident to use the program so you can join us on the night. If you would like us to help you, please don't hesitate to call or email the office to book a session. Our contact details are on the front of this newsletter and also on our website, we'll be happy to assist.

We'll ask members to register for the AGM prior to the night in order to ensure that we cater for all those wanting to join us. You can also find Board nomination forms with this newsletter.

Once again, if you would like training in how to set up and use Zoom, please book in early so we can ensure there's ample time to arrange a training session for you during October, in readiness for the 3 November AGM date. **Don't leave it too late – we'll cut off bookings by mid-October, to ensure we can provide all training sessions by Friday 30 October.**

Access Denied - Why We Need Mandated Accessibility Across All Australian Homes

As you read this, the Australian Building and Construction Board is considering a proposal to mandate minimum accessibility standards within the National Construction Code, which would affect all new homes built in Australia. We have provided a submission in response to the Regulatory Impact Statement on a number of models drawn from liveable housing design guidelines.

Liveable housing design is based around the idea that homes can be designed to suit the accessibility needs of everyone, a concept known as 'universal housing design'. Universal design aspects are already incorporated across mainstream housing in countries such as Norway; universal design is viewed as a logical requirement to address the diverse accessibility needs across society.

What's the problem anyway?

While preparing PDCN's submission, I was able to reflect on the Australian experience housing accessibility. It became increasingly obvious that the Australian housing market has failed to effectively respond to the accessibility requirements of the population. Just as we freeze in winter, or roast in summer in houses that are poorly designed for the Australian weather conditions, we are still living in homes that are not a good investment in terms of our accessibility needs. Instead we simply accept that our homes will either not suit our needs or will increasingly fail to do so as we age. This is a failing system that is being propped up by the massive industry in home care services and residential aged accommodation.



It doesn't have to be this way. So why don't we change it?

The problem lies in the very way that we think about accessibility. It is seen through a prism of bureaucracy, box-ticking and obstacles to be navigated. Accessibility is just an 'add-on' or an 'optional extra'. People who have additional accessibility requirements are forced to justify their need for modification via systems which focus exclusively on their physical limitations. Modifications are then considered through narrow criteria of 'best value', 'longevity' and 'relevance to specific goals'.

The major losers in the current model are people with physical disability, who are forced

to justify every ramp, every automated blind, the width of each doorframe. Why are we satisfied with such a piecemeal approach?

Equity can be achieved in many ways. Medicare is a great example, as it assumes the right of every person to afford basic healthcare regardless of their financial circumstances as a given. This is a starting point from which to build a system that ensures every Australian can access vital healthcare services free of charge.

Do we want to be a society that singles people out and only allocates resources according to what they *can't* do? When people are tied to a single modified home, what real choice and control does that afford them?

We now have the opportunity to examine current Government strategies to improve accessibility and think about how inclusive they really are.

Achieving mandatory universal housing design standards within the National Construction Code would be a huge step forward in providing people with physical disability a choice in how and where they want to live. It would mean that consumers know that their homes represent a good investment in their comfort and wellbeing across all stages of their lives. A level of general accessibility would be assumed across the market, providing greater options for people with physical disability in terms of where they live and what price they pay to live there.



That we must justify this, in light of Australia's commitments under the United Nations Convention on the Rights of Persons with Disabilities and various domestic disability inclusion strategies, is mindboggling. When one considers the projected growth figures for people aged 65 and over, it reveals an alarming lack of foresight.

How fantastic would it be if, like basic healthcare, accessible housing was just seen as an everyday right for everyone?

Hayley Stone
Senior Policy Officer

Happy 100th Birthday to Fred Kaad OBE

Happy Birthday to PDCN member Fred Kaad OBE who turned 100 years old earlier this month!

Fred is a veteran of World War Two who served in Papua New Guinea from 1942 until the end of the war in 1945. After the war, he held numerous roles in the civilian PNG administration, where he met his wife June with whom he had three daughters.

In 1962 Fred was captain of the PNG Athletics team at the Commonwealth Games in Perth. That same year he was appointed as Secretary to the Select Committee on Political Development which travelled around PNG, producing a report that resulted in the introduction of universal suffrage and the First House of Assembly of Papua New Guinea in 1964.



Injured in a plane crash in PNG in 1964, Fred was left a paraplegic, with extensive burns to his legs. Airlifted to Sydney he spent nearly a year at Royal North Shore hospital - while at the same time pursuing a postgraduate Diploma in Educational Administration.

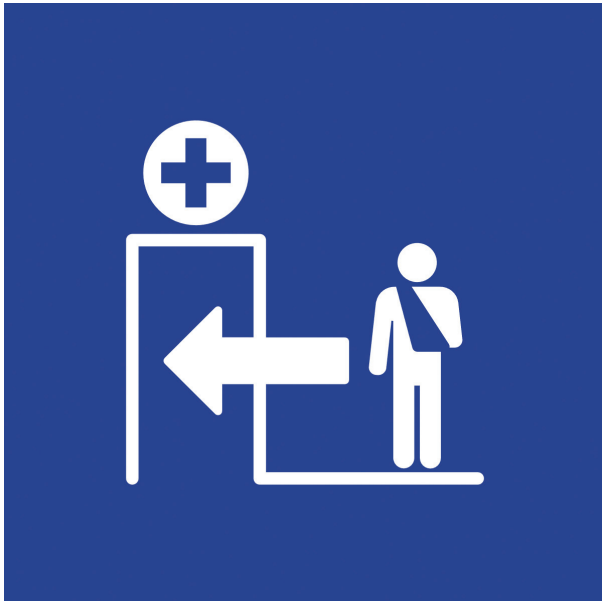
Once discharged, Fred went back to working for the PNG administration, and also completed his Master's Degree as a live-in student at the University of New England, the first wheelchair user to complete live-in study in a university.

In 1980 Fred was awarded an Officer of the Order of the British Empire for public service and services to the training of Papua New Guineans. Papua New Guinea later awarded him the Thirtieth Anniversary Commemorative Medal in 2005 and the Royal Papua New Guinea Centenary Medal in 2008.

Fred was one of the inaugural members of PDCN's Board when the organisation started in 1995, in charge of improving the NSW Government's Program of Aids for Disabled People (PADP) and Continence Aids Assistance Programs. He stayed on the Management Committee through to 2000 and is still an active PDCN member today! Fred lost his wife June 26 years ago, but his eldest daughter Gaynor has been his constant companion and carer ever since. Our best wishes to an amazing man on a life well lived!

A Health Passport for Hospital Admissions

The current coronavirus pandemic has shone a light on an issue that has affected people with disability for a long time – poor hospital experiences. Insufficient understanding of disability-related health care needs by hospital staff during admission means that people's health and wellbeing needs are not being adequately addressed, resulting in poor healthcare experiences. The issue here is that people with disability are often only treated for the acute condition that brought them to hospital, with no recognition that they have a disability that may also have support needs.



We are proposing the introduction of a 'health passport' as a standard resource across all NSW public hospitals. The concept of a health passport is not a new one. For example, the UK has health passports for children, and Queensland Health is currently trialling a health passport in Logan and Ipswich hospitals. These tools allow people with disability to let hospital admission staff know that they have a disability – and they may need extra assistance communicating, or support maintaining their health and safety whilst in hospital.

In order for the health passport to work as intended, NSW Health would need to integrate it in internal policy, so it becomes part of its protocols and all staff become familiar with the document. The obstacles are designing a document that can cover the diverse range of healthcare requirements across disability and getting NSW Health to agree to work it into its policies and roll out the health passport statewide. As NSW has a decentralised health system, some local health districts already have similar procedures. However, in order for it to be effective, it would need to be generic and mandatory across all local health districts.

Another requirement is that it can't be too onerous – hospital staff are not going to agree to something that will take up too much of their time. We all know that hospital emergency departments are incredibly busy places. It is not the goal to add to the workload, rather we seek to improve the process for patients.

Part of ensuring that the health passport is well received is making it useful and relevant across a broad range of specific health care needs. To that end, PDCN has commenced discussions with NSW Health, Health Consumers NSW, Blind Citizens Australia, Being, Council for Intellectual Disability, and Council of the Ageing.

The project is still in its early stages, but initial signs are promising that this is something

that we may be able to achieve as a positive outcome for people with disability. We will keep members informed around progress of the health passport and may be calling on members at a future date to participate in testing of any prototype that is developed.

We are keen to hear members' thoughts on what they consider would be useful to include in the health passport, the format it should take (either paper based, via an app, or both). We are also interested in any specific accessibility requirements that members might be able to speak to.

Ideally, we would like to see health passports become a mandatory part of the NSW hospital admissions process, resulting in improvements in the hospital experience for people with disability. We will keep you updated on this important advocacy work as it progresses.

Alice Dixon-Wilmschurst
Policy Officer



New Peer Group Starting in Glebe

We are in the process of establishing a new peer group based in Glebe which will meet on the third Thursday of each month. The Glebe Peer Group will be facilitated by a PDCN Peer Facilitator with personal experience of physical disability. Peer groups are a safe collective environment free from judgement; this peer group will focus on capacity building for members to encourage people with disability to enhance independence, speak up for themselves and achieve any goals within their lives.

The Glebe Peer Group will be topic based each month and along with members sharing their own life experiences, guest speakers will feature on occasion when relevant to specific topics.

This peer group is specifically for people with physical disability.

At this time, the group will operate online using Zoom meeting software. Once physical distancing restrictions are relaxed, members living in Sydney will be able to meet face-to-face at a location in Glebe. If you would like to find out more about peer groups, please call us on 1800 688 831 or visit our website and click on the '*Workshops And Support*' tab.

Chris Sparks in the Running for Aspire Award

After last year receiving an Order of Australia Medal, one of Australia's most prestigious awards, it seems PDCN President Chris Sparks is in line for yet another gong. Nominated by his former employer, Assistive Technology Suppliers Australia (ATSA), Chris has been shortlisted for the national Aspire Awards in the category Community Development and/or Advocacy. This is in recognition of his contribution to the development of ATSA as a national organisation that puts their clients, people with disability, first. It acknowledges his many years of speaking up for the needs of people with disability, particularly with regard to improving funding and access to high quality assistive technologies, while taking on government along the way.

In addition, it recognises his broader community advocacy work as President of PDCN, in his local area through voluntary membership on the local council access committee, and his tireless conviction that people with physical disability deserve better. Chris's drive ensures he is a worthy nominee.

The Aspire Awards, founded by Miranda Bain in 2015 and supported by the Funds in Court (a division of the Supreme Court of Victoria), provide an important opportunity to raise awareness about disability issues more broadly across the community, with the ultimate aim of supporting the development of an inclusive Australian society.

Pictured here receiving a medal of recognition for his nomination, alongside PDCN member and Australia's first ever Winter Paralympian, Ron Finneran OAM. Chris will need to wait until winners are announced at the Aspire Awards ceremony on Friday 30 October. We wish him the very best of luck on the day!



Matthew Kayrooz | Board Member Profile

What attracted you to the position on the PDCN board?

Two things – the first was the reputation of the Council as an active voice for people with disability, one of the few that had an impact, and I feel honoured to be able to assist them in continuing that voice. The second is through working in personal injury and knowing that even when people get compensated, they still don't necessarily have an 'everyday life' and more needs to be done to include them. PDCN works to ensure people with disability are included in all areas of life

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

My experience in business, finance and injury/insurance gives me an understanding of the mechanisms in society that should overlay the NDIS. I'm also aware of the levers to pull to make things better for people with disability and can use these skills to help PDCN focus their work and improve their lives.

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

Ensuring that people with disability have a voice and live independent lives. The NDIS is supposed to do this, but currently it seems more focussed on cost cutting. Its true purpose is being eroded and I feel strongly about fighting to make the NDIS truly work for people with disability.

There also seems to be a greater focus on mental health and intellectual disability currently and I'm concerned that people with physical disabilities are being left out, and their needs and voices lost. I'm keen to make sure that PDCN speak out and ensure that people with physical disabilities are included and catered for equally.

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

I love sport, physical fitness and being outside! Travelling and socialising are also great pleasures!



PDCN offers individual support for people with disability and parents of children with disability. The individual support provided so far has been a welcome resource for many of our members. Support has been provided in understanding rights and advocating for change in supported independent living with a significant and positive outcome for the people involved. We have also provided support in gaining access to the NDIS, in finding ways to build community and much more. Topics and areas of individual support can include:

- Information and a better understanding of any aspect of the NDIS
- Self-advocacy, assertiveness, and your rights or the rights of your child
- Resilience during and beyond the coronavirus pandemic
- Enhancing independence
- Relationships
- Adapting to change
- Practical living skills
- Travel accessibility (local, interstate and overseas)
- Accessing your community and activities.

If you would like to find out more about individual support, please call us on 1800 688 831 or visit our website and click on the '*Workshops And Support*' tab.



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