Donna brings lived experience and passion for inclusive communities to Participant Advocate role

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Donna Purcell pauses when asked about her guide dog Dora, a 5-year-old black Labrador, who sits beside her.

“I’ve had a bit of bad luck with my dogs,” she begins. “I’ve had four dogs, and my second dog was only about four when she got a rare kidney disease and passed away not long after.”

Donna is the new Participant Advocate at the NDIA.

And like the participants she serves and represents, she understands firsthand some of the challenges that can come with living with disability.

Dora, who faithfully assists Donna to navigate her world, is very unwell. In July, a routine check-up revealed stage 5 lymphoma.

The news came only two weeks after Donna lost her third guide dog, Emily, by then a beloved pet. So soon after losing Emily, Dora’s cancer diagnosis was devastating.

“It was a shock,” Donna says. “But once you have a plan and once you make that decision on treatment, then I guess my philosophy is, well, we don't have a choice. We have to deal with this.”

Donna agrees her calm resilience comes from a lifetime of navigating hurdles.

“Like many people with disability, I have had to overcome many barriers and difficulties,” she says. “I think people with disability become great problem solvers and are great at finding different ways of doing things. I know for myself, no problem is too big.”

Diagnosed with a rare, degenerative eye condition at five, Donna lost her vision gradually and was blind by her late 20s. Growing up vision-impaired in the far west outback town of New South Wales’ Broken Hill, she had little support.

“It was a struggle, I didn't get any support at school,” Donna says. “My mother, in particular, was almost in denial.

So I had grown up thinking that it was something wrong, it was something that needed to be hidden, not talked about. I was embarrassed and almost denied having a disability.”

Donna’s tough early experiences shaped the person she would become – a passionate advocate for the rights of people living with disability.

Today, she lives with her husband in Sydney and is a recognised leader in designing and developing strategies for inclusive and accessible workplaces and communities in Australia.

“My role at the NDIA is to ensure that the participant voice, that participant lens, is pulled over all of our work, regardless of what that is, that we're truly thinking about, ‘What is this going to be like for the participant? What is the experience our participants are going to have because of this change?’

“And most importantly along that journey, making sure that we're involving participants in that decision making.”

Donna believes celebrating and acknowledging people with disability on International Day for People with Disability (IDPwD) is important on many levels.

“It gives people with disability that day where there's permission to have a voice and to speak up where they may not normally do that, because of fear of discrimination or being judged, where to know it's okay to say more, to have a greater presence,” she says.

“We need to see people for who they are and what they can do, not for their disability.”

Donna is a NDIS participant herself and says it has given her more choice and control over her life.

“It has made me more confident in making choices about what is important for me and how I maintain my independence,” she says. “I've been able to engage a support worker three times a week, and we do a six-kilometre walk before work, so I’m getting that fitness time, which is so important for my wellbeing.

“And it means that happens at a time and place that works for me, rather than waiting and relying on someone else.”

In the coming months, Donna and her husband will navigate an uncertain path ahead with Dora, who has been undergoing chemotherapy since July.

“It might sound like I’m saying this because she’s my dog, but Guide Dogs New South Wales say she's one of the best dogs to graduate from their program,” Donna says.

“It’s a very close relationship and you get very emotionally attached and, I guess you have to have a lot of trust in that little creature and it just seems so unfair, I mean, she's only just turned five and it just seems so unfair. We’re just hoping she’s one of those dogs who gets through.”

Donna’s story showcases the impact we can all have when we see people for who they are and the things they can do.

To help celebrate the day you can download the IDPwD pack including a social media pack, poster, virtual meeting background and email signature block on the IDPwD page.

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