



side by side

The Newsletter of Side By Side Advocacy

Summer 2021

www.sidebysideadvocacy.org.au

Hello Everyone,

Welcome to the Summer edition of Side By Side. As we emerge from lockdown, the team continues to provide advocacy in a way that suits the person seeking advocacy and that optimises safety.

Today is International Day of People with Disability, a United Nations observed day that aims at increasing public awareness, understanding and acceptance of people with disability. The Australian Government has been supporting International Day of People with Disability since 1996.

The theme for International Day of People with Disability in 2021 is 'Leadership and participation of persons with disabilities toward an inclusive, accessible and sustainable post-COVID-19 world'.

We hope the theme results in more people considering ways that people with intellectual disability can be encouraged and supported to take on meaningful decision making roles within organisations – including as members of management committees and Boards.

We also hope that the day prompts people to reflect upon the importance of advocacy in supporting people with disability to have their voices heard, rights upheld and needs met.

At Side By Side Advocacy, our vision is for a world where all people are equal and valued, where diversity is celebrated, needs are fulfilled, and opportunities realised. Until that vision becomes reality, we encourage you on this International Day of People with Disability to use the opportunity to have impactful conversations. Let's really talk about the importance of meaningful inclusion in contemporary society where people with disability take their rightful place as valued citizens.

Read on to

- Catch up with the Inclusive Governance Team and find out about their presentation to the Australasian Society for Intellectual Disability Conference
- Hear from Carole about the importance of speaking up
- Meet the newest addition to the Disability Royal Commission Team, Sarah Mitchell
- Read an Easy Read document about voting in local government elections
- Access copies of the International Convention on the Rights of Persons with Disabilities – including in Easy Read format
- Watch a video about why advocacy matters
- Learn about a new role on the Board at Side By Side Advocacy
- Add some dates to your calendar
- Note some emergency contact numbers
- Meet long time Citizen Advocate, Jeanette Bastian.

Everyone at Side By Side Advocacy wishes you a safe and happy holiday season.

We look forward to catching up with you again soon.

Kim Roots

Executive Officer - Side By Side Advocacy



Inclusive Governance Project Update

Side By Side Advocacy's Inclusive Governance Project Team - made up of Katrina, Will and Bernadette - attended the ASID Conference. This conference is an annual event run by the Australasian Society for Intellectual Disabilities. This year it was online because of Covid issues.

During the 2-day conference, the Inclusive Governance Team gave a presentation about the Inclusive Governance Project – what it is about, how the research is being done, and what the early results are. This presentation was pre-recorded.

The Team then went live and responded to questions about the interviews they have done, whether the experiences of people with and without disability are similar, and who they have talked to about legalities involved in governance of community organisations.

It was great to get the message of inclusive governance out to a new group of people throughout Australia and Aotearoa New Zealand.

We are still interested in speaking with people who have had experience either serving on a Board or supporting people who are on a Board. We are interested in speaking with people with and without an intellectual disability.

If you would like to find out more about how to participate in this project, please contact Bernadette, who would be happy to talk to you.

Bernadette's contact details are 0411 952 974
or igp@sidebysideadvocacy.org.au



Images from the Australasian Society for Intellectual Disability (ASID) Conference.

See below the team presenting and responding to questions at the ASID Conference.



The importance of speaking up!

Many people with disability have their concerns ignored with big consequences.

That is something that Carole experienced recently. She discovered that her feet were loose in the boots she'd had especially made so that it was difficult for her to walk.

Not being able to walk safely meant Carole was sitting in her chair most of the day.

When Carole first mentioned her issues with the boots, nothing was done. The bootmaker dismissed her concerns saying it was neuropathy. Neuropathy is when nerve damage leads to pain, weakness, numbness or tingling in one or more parts of the body.

Carole knew that the boots really were too big, so she did her own research to find a podiatrist who specialises in managing complex foot issues.

She contacted Royal North Shore Hospital and got a second opinion. The expert from the orthotics team checked out the boots and agreed with Carole. There was a real issue.

'He listened and took my concerns seriously. If I hadn't spoken up, nothing would have been done. I now have a podiatrist who I trust and who is helping to keep my feet healthy.'

Carole has been assisted to have padding in her boots as a short term solution. She is exploring having new boots made that fit. This will reduce the risk of falls.

'I can get back to doing the things I want to. Like joining an art group and learning guitar.'



Carole relaxing at home

Meet Disability Royal Commission Team member, Sarah Mitchell

We are pleased to report that Sarah Mitchell joined Side By Side Advocacy in August 2021 as an Individual Advocate in the Disability Royal Commission Team.

Sarah has experience working with people with disability and is passionate about supporting people to lead ordinary lives that are meaningful to them, whatever that looks like.

Sarah has completed a Bachelor of Communications (Social and Political Science) and a Bachelor of Creative Intelligence and Innovation and is excited to bring these skills to the area of advocacy.

Sarah says, 'I am extremely happy to be a part of Side By Side Advocacy. I feel very grateful to have joined such a knowledgeable and passionate team.'

Disability Royal Commission advocacy support is for people with disability (or family members or carers acting on their behalf) who may have difficulty in

communicating or understanding how to engage with the Commission.

If you, or someone you know, lives in the northern suburbs of Sydney and needs additional support to engage with the Disability Royal Commission, contact Sarah and the team at: DRC@sidebysideadvocacy.org.au

If you are outside of Sydney, you can find an advocate in your area, via the Disability Advocacy Finder tool on the Department of Social Services website: disabilityadvocacyfinder.dss.gov.au

If you are affected by the Royal Commission and want to access counselling, here is a link to some counselling services: [Counselling and Support](#)

If you need help but are not sure who to ask, you can contact Side By Side Advocacy, and we will point you in the right direction.



Getting ready for local council elections on 4 December

Local Government elections in New South Wales decide who will be on the council in your area. There is a Local Government election on 4 December 2021.

The Council for Intellectual Disability has an Easy Read document that says

- what the Local Government elections are
- the ways you can vote.

Here is a link to an Easy Read document about voting: [Your right to vote in NSW](#)

There is also a video about how to vote: [How to vote video](#)

Convention on the Rights of Persons with Disabilities

Most of us know there is a Convention on the Rights of Persons with Disabilities. Many leaders and organisations claim to embrace the content of that Convention - but how many people really know what it says?

With International Day of People with Disabilities today, we have attached links to the Convention and to an explanation of the Convention in Easy Read format that has been prepared by UNICEF.

Easy Read document: [It's about ability – An explanation of the Convention on the Rights of Persons with Disabilities](#)

General information: [Convention on the Rights of Persons with Disabilities](#)

Advocacy for people with disability

As an advocacy organisation that lives and breathes independent advocacy, we are keen for others to be aware of the importance of advocacy and the availability of free advocacy support.

Below is a link to a video that discusses what advocacy is and why it is important. The video comprises a thoughtful discussion between John Armstrong and Bob Lee who have been respected advocates for many years. The video makes clear that advocacy can be far more than a reactive quick fix to a particular issue.

Here is a link to the video: [Advocacy for people with disability](#)

Join the Board of Side By Side Advocacy

Side By Side Advocacy is currently on the lookout for a new Treasurer. This unpaid role would be suitable for someone who has accounting and financial expertise and the motivation to work for social justice for people with disability.

Here is a link to the advertisement: [Treasurer at Side By Side Advocacy](#)

Meet the People of Side By Side Advocacy

In each edition of Side By Side we get to know someone from the Side By Side Advocacy community. During the heart of the Sydney lockdown, Kim caught up with long term Citizen Advocate, Jeanette Bastian, who shared her experiences and insights.

Kim: Could you tell me a little about yourself?

Jeanette: I am a retired, secondary, science teacher. I taught at state and private schools as well as Tafe. I am married with kids and grandchildren. One of my children lives in England with his wife and two children so Covid restrictions are hard. I really want to visit them again. I have a range of interests that include book clubs, yoga, podcasts, learning Spanish, cooking, and walking my Labradoodle who is a big bundle of enthusiasm.

Kim: How did you first hear about Side By Side Advocacy?

Jeanette: I have been friends with Michelle Donnelly who is a longstanding Side By Side Advocacy Board member. I heard about the organisation from her.

Kim: What is your role at Side By Side Advocacy?

Jeanette: I'm a Citizen Advocate. I was told about Citizen Advocacy some years ago but did not have space in my life. I had three kids and a job. When I retired, I did have time and wanted to volunteer in some way.

The concept of being a friend to someone appealed to me. After a lifetime of meetings, I also liked the fact that I could act independently, and my actions could make a difference.

Kim: What does being a Citizen Advocate involve?

Jeanette: I see my role as being a friend who occasionally challenges bureaucracy. There are a few parts to that.

I feel the need to challenge things when the person I'm matched with is expected to settle for less than I would accept for myself. I apply an ordinary perspective – not a bureaucratic perspective.

A simple example was when staff had chosen a television show for David that was Scandinavian and had subtitles. David cannot read. The choice of program did not make sense if David's needs were being prioritised. The show must have been chosen for staff with David's needs judged to be less important. I questioned that.

Another example was following up when a valued possession went missing. Nobody was being dishonest – they just were not focused on David's needs. I made sure it was found and returned.

I also questioned when David was not being supported go outside his home.

This was nothing to do with Covid. I followed up to make sure he had some variation in his days.

I basically keep my eye on what is happening and ask questions. People behave differently when they know that someone is watching.

I also help build social currency for the person I'm matched with. I am friendly with staff and model positive interactions so that staff are more likely to see them as a valued person.

It can be a challenge to both maintain good relationships and question problematic practices.

Kim: Could you tell me about your matches?

Jeanette: I started as a Citizen Advocate in 2013 and have been matched with two people. One was a woman called Norma who passed away in 2018. I met with her regularly and gradually built a connection. Connecting and building trust took time. I think she started to trust me when I kept turning up with fresh clothes when she had broken her leg and was in hospital.

People would also visit Norma in their professional capacity but the dynamic was different. They had other clients and would be looking at their watches after they had done what was required for their role. They had lots of competing interests and were being paid to perform a function. I was there because I wanted to be and just for Norma. I was there as a friend and was always attempting to see things from her perspective. I am not being critical of the workers but the distinction in perspective results in different priorities.

Norma had not had the chance to try many things in her life. Facilitating experiences was not hard or expensive. It just involved valuing her enough to think about what would make her happy and a small effort.

After Norma's passing, I took some time out before being rematched with a man called David who lives in a group home. Covid delayed us meeting face to

face.

We are still building our connection.

One of the things that I have noticed is that people don't say goodbye to people with disability when they know they are moving on. They just disappear. That must be awful. It creates a sense of uncertainty about who to trust.

If that is your experience, it makes sense to be cautious and take time to trust that someone is going to keep turning up.

David is beginning to understand that there is someone just for him.

Kim: Has being a Citizen Advocate made a difference in your life?

Jeanette: I have received an education in the world of disability. I have learnt how hard it is to be heard by government.

Things are done for people with disability that would never be done for others and that needs to be called out. The attitude is sometimes that they won't know the difference.

One example I was told that has stayed with me was where a person with disability was given chopped apple with the core left in. The person relating the experience called that out saying, 'We don't eat the core in our house. Do you?'

I have also formed two positive friendships and that has been lovely.

I now see things from a different perspective and that is broadening for me.

Kim: How does Side By Side Advocacy support you?

Jeanette: It is impossible to describe the support from Deb. She always understands what I am talking about, is supportive and makes helpful suggestions. I also find out about helpful things that may be available like taxi

vouchers.

I have also had training and met with other advocates.

Kim: Why do you think Citizen Advocacy is important?

Jeanette: Someone needs to speak up for people who don't have access to power. Some people need help to navigate the system – to be heard and to get things done. We need more Citizen Advocates.

If you would like to become more involved with Side By Side Advocacy, let us know and we can explore possibilities!



Jeanette with David

Dates for your calendar

3 December 2021: International Day of People with Disability

27 December 2021 – 3 January 2022 – Side By Side Advocacy Office will be closed

(Office reopens on 4 January 2022)

1 January 2022 - New Year's Day Public Holiday

3 January 2022 – Additional Public Holiday (because New Year's Day is on a weekend)

26 January 2022 - Australia Day Public Holiday

Emergency contact numbers

Emergencies sometimes arise over the holiday season.

In case of fire, medical or police emergency, dial **000**.

Here is a link to some other emergency contacts that may be useful:

[Emergency contacts](#)

Have your say!

Do you have any suggestions about how we could do things better or differently at Side By Side Advocacy?

If you do, we would love to hear from you! You can use the contact information below to tell us.

Contact details for Side By Side Advocacy

Phone: (02) 9808 5500

Email: info@sidebysideadvocacy.org.au

Website: www.sidebysideadvocacy.org.au

Address: Shop 1, 30-32 Herbert Street, West Ryde, NSW 2114

Office hours: 9am to 5pm

Side By Side Advocacy is a short distance from West Ryde Railway Station.

There is a bus stop at both ends of Herbert Street.

There is time limited on street parking.

Side By Side Advocacy promotes and upholds the rights, needs and interests of people with disability to enable full and meaningful participation in the community.

We recognise that people with intellectual disability experience particular barriers in having their voices heard and needs met and for that reason we specialise in providing advocacy for people with intellectual disability.



side by side advocacy