

Inform Podcast
Episode 10: Self-Advocacy

Intro: National Self-Advocacy Anthem song plays

Kirby Fenwick

Hello and welcome to Inform, a podcast where you'll be hearing from people with disabilities, as well as industry experts, on a range of topics.

I'm your host, Kirby Fenwick.

In this episode of Inform, we'll be discussing self-advocacy.

At the start of this episode, you heard a snippet of the National Self-Advocacy anthem, a song created from the thoughts and words of people with disabilities who helped to build Voices Together, an important self-advocacy project we'll get back to later in the episode.

Also in this episode, we'll define what self-advocacy is and why it matters. We'll look at the history of the self-advocacy movement in Australia and the work of the Self Advocacy Resource Unit. And we have some great advice for anyone looking to explore self-advocacy for themselves.

Today, we'll be hearing from Colin Hiscoe. Colin has been involved in self-advocacy since the early 1980s and is the president of Reinforce. We'll also be hearing from Sue Smith, from the Self Advocacy Resource Unit, or SARU. Sue, like Colin, has been involved in self-advocacy for many years.

Kirby Fenwick

So, what is self-advocacy?

Colin Hiscoe

For me it means being able to stand up and to do things for myself and to be able to get or to try to get what it is that I'm wanting

My name is Colin Hiscoe. I'm the president of Reinforce. And I have also been involved and paid as a paid person to work on the Voices Together.

Self-advocacy is, is also making sure that we have the same basic human rights as anyone else in the community

Sue Smith

Self-advocacy is many different things. But the main thing about it is it's a movement it's considered to be a civil rights movement, particularly for people with intellectual disabilities.

My name is Sue. I work at the self-advocacy resource unit, or SARU as everyone calls it. And I've been involved with self-advocacy for nearly 40 years.

Self-advocacy also includes groups run by people with acquired brain injury and groups run by people with complex communication support needs such as the group Deaf Blind Victorians, but it started in the late 60s, came out of Sweden, it spread all around the world really quickly.

Kirby Fenwick

The beginnings of the self-advocacy movement can be traced to Sweden where in the late 1960s, people with intellectual disabilities were supported to create and lead their own leisure clubs. By the early 1970s, the idea had spread to the UK, Canada and the United States.

In 1980, Reinforce became the first self-advocacy group in Australia. Run by and for people with intellectual disabilities, Reinforce was involved in a series of direct action protests throughout the 1980s and they still exist, and self-advocate today.

Throughout the 1980s in Australia, self-advocacy groups flourished. Together, people with disability had a strong voice. And they used that voice to speak out about institutions, rights in sheltered workshops, changing community attitudes and their right to equality.

In the 1990s, funding for many self-advocacy groups was cut and forced many groups to close their doors. But in 2008 the Victorian Government funded the Self Advocacy Resource Unit or SARU. Support provided by SARU has seen the number of self-advocacy groups in Victoria grow.

Sue Smith

And it's really, every group is unique. But they all share one thing like Colin was saying, speaking up, making change happen, working with government, friendship, and working with peers.

And it's about civil rights and people having their rights and having their voices heard.

being a self-advocate, but particularly part of a group, people call themselves self-advocates. And it's this sense of identity and a sense of strength. That I'm a self-advocate.

So, people wear it as something with pride.

Kirby Fenwick

For Colin, who joined Reinforce in the early 1980s, finding his place in the self-advocacy movement was like having a weight lifted from his shoulders.

Colin Hiscoe

In the beginning, it's like I had this dirty big weight lifted from my back. I didn't know where to go. I didn't know what to do. I didn't know how to get support from people. I knew nothing about speaking up and self-advocacy. And when I got to this conference. You know? Wow. It just absolutely blew me away. It was almost, it was almost like this dirty big 10 tonne brick or whatever it was that was on my shoulders had been lifted off.

And the reason I'm saying that is that their stories were similar to mine. So, their stories were my story and my story was their story. We were almost saying the same thing, but maybe in different words but meaning exactly the same thing. And I just wanted to be involved with this really fantastic group. And so, I asked around, how do I do it. Oh, you just become a member and then we take it to the committee and then we vote and find out if anybody knows why you shouldn't become a member or anything like that. And then I got a letter saying that I'm a member. And then, that was in April, and then in May, I was just about working every day of the week, as, as many as I could. Try trying to fight for the same basic human rights as anyone.

Kirby Fenwick

As Colin and Sue have explained, self-advocacy is about the rights of people with disabilities to have their voices heard, listened to and respected. And Colin says that there are many reasons why someone may need to self-advocate

Colin Hiscoe

I think when they're not getting what they're wanting and nobody's listening, and no one's taking any notice of them. You know, oh, that's too hard, too difficult, you haven't got the money just sit down shut up, you know, be a good boy or a good girl. So, I think it will be not getting the same basic human rights as anyone else has in the community.

Kirby Fenwick

More than four million Australians have a disability. That's 1 in 5 people. If you're not one of those millions of Australians with a disability, it's likely that you know someone who is. But Australians with disability are some of the most discriminated against people in the country. Of the complaints received by the Human Rights Commission, disability discrimination tops the list.

A collective voice or an individual one, self-advocacy is a way in which people with disabilities can have their voices heard.

Colin Hiscoe

Why does self-advocacy matter? Why shouldn't it? You know, we have the same basic human rights as anyone else in the community so, why can't we?

I sometimes think that there are still a lot of people out there, you know, people with disability in groups homes or maybe at home or maybe living in a flat or a unit or whatever. But they still don't know what their basic human rights are. And I think that's why it's up to organizations like reinforce and SARU and a couple of others

that we're there, and we're getting ourselves known. We're getting information out there to people.

So, we have, I think it's a three, a quarterly newsletter, which is three in a year, we send that out, we send it to group homes, we send it to our members, we send it to associate members, we sent it to members, we send it all over the place. And it's amazing how even just that newsletter, you know, they might not, they might not want to know anything that's in that newsletter. But the thing they do want to know is that there is an advocacy group out there fighting for the same basic human rights as what they are. And there's a phone number, so they'll pick up the phone and ring. So that's yeah, self-advocacy is really, really important.

Kirby Fenwick

The power of self-advocacy often lies in people coming together to use their collective voices. Colin recalls a workshop run by Sue that demonstrated just that.

Colin Hiscoe

And what it was, we got one person to say the word self-advocacy, and then all you could hear is self-advocacy (whispered). And then Sue was asking, can people hear that? No, not really. And then everybody in that room twenty or thirty people, depending on how many, they all, they all said that one word. And you can see people covering their ears because it was that loud. So yes, I believe it's the numbers business and the strength in numbers, you know, so if we're having trouble, then we can go and get support from other self-advocacy groups or maybe run a campaign.

Kirby Fenwick

But the power of self-advocacy is about more than just the collective voice. It's also about the way it can change people's lives

Colin Hiscoe

There's this member of Reinforce, and when I first met her and she was coming to these meetings, I'm not going to use names, you know, we might ask her what do you think about this? And she'd be just looking dumb, dumbfounded and didn't know what to do, didn't know what to say. I don't know. Oh, do you think you've got rights? I don't know. And then eventually, that was about what, three, four years ago maybe. Now look at her. You know, she's, she's just grown that much. It's incredible. And I think it's the power of the self-advocacy groups and the power of the people and supporting each other to be able to achieve what it is that you want.

Kirby Fenwick

The Self Advocacy Resource Unit or SARU plays an important role in providing support to self-advocates and to self-advocacy groups

Sue Smith

And by support, it's about what those groups want from us. So, it might be, they might want some training. Reinforce at times gets us to help with strategic planning. It might be help to make resources, it might just be using our favourite machine at

SARU which is a tower that burns 20 DVDs at one time, so burning DVDs because a lot of groups make videos and want to get their message out through videos.

The other role we have is to help new groups start. So, when we first started in Victoria, there was about 10 groups around now there's about 21 self-advocacy groups in Victoria. Victoria has more self-advocacy groups than any other state in Australia.

Our other role is to support networking. So that can be for instance, many of the groups wanted to start their own network so we provide the support that they want. So, it's all directed by the self-advocates, not us.

But one of the things that we are not allowed to do is advocacy. And why that is, is because really our role is to provide the resources and the skills and advice that the groups need so they can do it.

The other thing we do is make resources, so we either work with groups to make their own resources that includes videos or training. We also, we will make resources that we can see there's a gap in.

An example of that was the Voices Together project where we travelled around Australia and met with all the self-advocacy groups in Australia in different locations. And we paid them to co-produce resources for the website. And we consulted with them. We did two trips around, about what they wanted on their website.

Kirby Fenwick

The Voices Together project is an online self-advocacy resource designed by and for people with disabilities.

Colin Hiscoe

Voice Together is a list of resources that we've all made as part, as part of a self-advocacy movement. So, we might be saying that we want this resource or we want that resource. One of the things I've been working on, I've been paid to facilitate two sessions with Sue and with Sally, who was working on the project as well. And they were in, they were in South, South Australia and the other one in Tasmania.

Again, I was paid to proofread and give input into the resources on the website. And my favourite resources were the How to sheets. And I believe that's because it gives you information that you needed to know about something. And the one that I think I felt really passionate about was your rights when you go to the doctor, and the doctor is speaking to your support worker rather than speaking to you. And we just did a project where we're talking about good and bad points, with reinforce about people with disability and doctors, that was really well received.

Sue Smith

Yeah, it was all based on literally, as Col said, when we travelled around, we asked the groups what they wanted. And I think I mean, it's a massive website. There's a

lot on it. There's 100 videos and lots of lots of resources. But it was really, from what self-advocates said they wanted on the website and Sally and I would just write it all down. And then we also had a steering group that consisted of a rep from every state, a self-advocate coming over to Melbourne, and by the end of it, we'd managed to develop and make and have on the website, all the resources that were asked for, which was a great thing. but to me it was really not co design where people give you advice about how to do things. It was really the self-advocates making the content and really being involved in all aspects of it.

Kirby Fenwick

There are many reasons why you might want to get involved with self-advocacy and with decades of experience between them, Colin and Sue have some advice for anyone looking to pursue self-advocacy.

Sue Smith

the power of people joining together to have a voice, I have seen for many people be life changing and provide so many opportunities. It's just, I'm always in awe of what the groups are doing and, and working together and having a strong voice.

But also, the passion. I mean, Reinforce has been going for what are we up to now Col forty years, I've been involved in self advocacy for 40 years as well. But the power of the groups to make change and being part of the sort of self-advocacy movement and being part of a group also links you to who can actually do something about what you're speaking up about. Whereas a lot of times, I would say, my experiences over the years, that without that, around you, the people around you supporting it, sometimes it can be hard to be heard.

Colin Hiscoe

I wish say, like out of 100 people, I wish only one would take that first step and get what it is that they're wanting. And then you know that what you've been talking about has worked and somebody's listened and gone ahead and made that first step.

Because I think some people with a disability, sometimes when they're just, they're standing up for their rights again and again and again and again. And then if you keep getting knocked back time, after time after time, people are just gonna think what's the bother. I know I'm not gonna get anything because of my past. So, I don't want to bother. And I think that's where self-advocacy groups like reinforce and SARU and a few others come in really handy and we can set and support that person.

Colin Hiscoe

My tips for advocating for yourself, if you're not sure how to do it, or you don't know how to do it or you just new at trying to do this maybe ring us at Reinforce, ring the SARU, ringing any other advocacy group that might be around in your area, that are closer to you. But one tip I would like to give you, and it's a bit of a plea. And that is to please don't give in. It's going to be hard. And you're gonna have knockbacks and yet, you're gonna feel 'Oh, Crikey, this isn't gonna work. I'm not getting anywhere.

What am I gonna do?' Please don't give in. Please make that phone call. Get help and support from somebody.

Kirby Fenwick

Thank you for listening to Inform, a production of Independence Australia. Inform is hosted and produced by Kirby Fenwick. Our managing editor is Alison Crowe.

Our thanks Colin Hiscoe and Sue Smith for being a part of this episode and sharing their experiences and their knowledge. .

You'll find links to the resources mentioned in this episode, plus more, in the show notes at informonline.org.au

Inform is funded by a National Disability Insurance Agency Information, Linkages and Capacity Building grant. Being grant funded means that we are an independent production. Our aim is to help people with disabilities better connect with their communities.

So, if you have a story to tell or an experience to share, get in touch by emailing us at inform@independenceaustralia.com That's i.n.f.o.r.m at Independence Australia dot com.

We'll be back soon with more but in the meantime, you can find all our episodes at www.informonline.org.au/listen, or subscribe to Inform on your preferred podcast listening platform to stay up to date.

Outro: National Self-Advocacy Anthem song plays