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Helping people fight for their rights

**Kylie’s story**

I have a number of conditions, I was born with spina bifida and scoliosis. I’m also in renal failure at moment, so I’m on nocturnal dialysis and awaiting another transplant. I had a bone disease in my hip as a child and am also looking at a hip replacement in the next few years.

I am a single mum, with a young daughter. I used to work managing an Op Shop and cleaning houses while studying to become a kindergarten teacher. Mobility-wise I’ve been up and down over the years, depending on whether I’m doing the right things to take care of myself. If I stop doing the things I should be doing, like my chiropractic treatments and physiotherapy program, I go downhill real fast. My spine gets very stiff and sore until eventually it ‘locks up’, my nerves get compressed and it affects my ability to walk.

I live in the Barwon region and have been part of the NDIS trial there. Up until the transition to the NDIS in January 2013, I had an individual support package (ISP) that included chiropractic treatment. When I do my chiropractic care and the other things I need to do to look after myself well, I am able to walk with a limp for most of my mobility needs.

The state and federal governments had an agreement that no one would lose services under the NDIS. But when I got my new package under the NDIS, it didn’t include any physical therapies, including chiropractic treatment, only home and garden maintenance assistance. When I asked why, they told me the NDIS doesn’t fund physical therapies, and I would have to fund them myself if I wanted them.

I was stunned really, when they told me that. I was like, ‘What? That’s it?’ They gave me a folder with all these pieces of paper, which said if you weren’t happy with the decision you could ask for an internal review. So I wrote a letter and emailed it to my NDIA worker. They took a long time to get back to me.

I dipped into my savings to pay for my chiropractic treatment. I still had savings at that point. But eventually my money ran
out and I could no longer self-fund the therapy, for a number of months. Over that time my mobility decreased, I had to stop working, I couldn’t do what needed to be done to live a normal life. I also had to put my studies on hold.

Eventually the decision was reviewed and upheld, to not fund my chiropractic treatment. In amongst the fine print it said you could request an external review, but it didn’t outline how to do it. This was December 2013.

I hit a low. I was starting to struggle with depression and emotional stuff because my body was falling like a stone. I’d gone from working and studying to barely being able to walk from one end of the hallway to the other. So between the physical struggle of it, the increased pain levels, and the doctors prescribing more and more powerful pain killers that create a bit of a fog in your mind, nothing was clear any more.

I thought ‘I can’t do this by myself anymore, I need someone to help me’ and I did a google search for disability advocacy in Geelong, and found a phone number for RIAC (the Rights Information and Advocacy Centre).

So I called RIAC and James Keith, who is a RIAC advocate, came to my house. I had a review meeting coming up that I had to go to, to discuss my plan for the next year, and after everything that had happened I was terrified of it. I’d had so many bad experiences that I was terrified of going by myself to the meeting. So James offered to come to the meeting with me.

I then went on to the Administrative Appeals Tribunal to fight for chiropractic treatment to be included in my NDIS plan. I went because of need basically, basic need. I couldn’t do the things I needed to do, I couldn’t take care of my child the way I wanted to, my house looked like a bomb had gone off in it and I had not much to lose.

Without RIAC and the legal aid lawyer it would have been almost impossible, because I had no idea where I was going and what I was doing. Going to the tribunal was also very intimidating.

But eventually I found out the tribunal had decided in my favour, that chiropractic support was a “reasonable and necessary support” for me, as they say. I spent the whole week walking around going “Wow, wow, wow”.

At the tribunal I presented my own lived experience as evidence. That was the first time they had taken lived experience into account. Before that, evidence heard was mainly from providers or therapists or medical models. But while sometimes research and evidence can be shown to be invalid, you can’t ever say someone’s lived experience is not valid. And now if a person says they’ve had this lived experience, that’s something the NDIS workers will need to take account of in their plans, they can’t just dismiss it as something that doesn’t count. It’s a really good start to actually listening to people who are experts in their own conditions, having lived with their conditions all their life, over a medical professional who sees you for maybe 15 minutes every two or three months, who actually doesn’t live with it.

In terms of any advice I would have for other people thinking about advocating for their rights, there’s millions of things I could say, but I guess the main thing is “find someone to help you if you need it, and keep moving forward, don’t go backwards”.

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Kylie with RIAC advocate James Keith at the Geelong RIAC office. PHOTO: Phil Roubin

**Rights Information and Advocacy Centre**

Advocacy is so important to people with disability in Australia right now. They are at a point in history where they are able to make choices they have never had the opportunity to make before. Advocacy services can support and empower people with disability and their family and carers to make those choices and start to live their lives as part of the community. This is a very new concept to people with disability, and it will take most people time to realise they have opportunities that have not been afforded them before.

The transition and thought processes that must occur both for people with disability and the service sector that supports them, will not shift overnight. Advocates need to be there to keep reminding people they have the right to make choices and the power to make the decisions that affect their lives. This is a huge shift and one they don’t quite believe at this moment.

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The Rights Information and Advocacy Centre (RIAC) has been servicing the NDIS Barwon trial site for two years, both with advocacy support and through the External Merits Support Program. During this time we have supported many people in the trial site, including 20 appeals through the Administrative Appeals Tribunal.

We have seen that the need for advocacy is now greater than ever. The transition to the new scheme has not been without its issues and people with disability have had many difficulties transitioning to the new scheme. And whilst the NDIS has brought new issues and problems for some, old issues and problems also still persist in the wider community, requiring continued information sharing and advocacy support.

*Leah Kateiva
Acting Chief Executive Officer
Rights Information and Advocacy Centre*