

Interview with Leanne Dowse

Leanne Dowse

Professor, Chair in Intellectual Disability Behaviour Support

University of New South Wales



Please tell us about your career to date including your current role.

As a speech therapist working with people with Intellectual Disability during the time of deinstitutionalisation I learned about the need for understanding the clinical as well as the social context of disability. Many changes happened during that time that we were not really prepared for, particularly what it meant for people with intellectual disability to live in the community and what a community needed to be like to be welcoming of them. I moved to a research position at the University of NSW where I worked with the first academics in Australia working around and understanding the social model of disability. Even though we think that is a well-established idea now; it really only **emerged in Australia in the 1990's. Projects that I worked on really took seriously the idea that disability is primarily the social consequence of living in a society that values normalcy above all else. From those beginnings of disability studies in Australia I now hold the Chair in Intellectual Disability Behaviour Support at UNSW, and this year was appointed UNSW's first Professor of Disability Studies.**

What or who were your key influences?

As I have moved through an understanding of disability from a clinical to a more social perspective my biggest influences have been people with disability themselves and their organisations and the experiences they have shared with me through my research. My PHD was about self-advocacy so I worked with self-advocacy groups both in the UK and Australia. I have also had many academic colleagues who have taught me the skills needed to be a good scholar and researcher.

What is the IDBS and its strategic roadmap?

The Intellectual Disability Behaviour Support Program (IDBS) was established under the Chair of Intellectual

Disability Behaviour Support which I hold. It was a NSW Government funded initiative aimed at addressing issues for people who have intellectual disability or cognitive disability and what we think of as complex support needs. People might have complex behavioural issues or they might have dual diagnoses, they might have contact with the criminal justice system, they might have drug and alcohol issues, so the work tries to broaden out what we understand by the intersection of the social and the clinical and intellectual disability. The program of work focuses on **bringing research to policy and practice. I think that's probably the most important work. People often have an expectation of researchers that we have all the answers to the difficult questions at our finger tips. What we have really understood over the time of designing and moving the program forward is that for research to have an impact on those who need it or want it, it's got to be a very collaborative process from the word go.**

The work of the IDBS program is focused on **translating and exchanging knowledge that's co-produced.** We work with organisations and through them with people with disabilities and practitioners. Almost all

“The IDBS program is focused on translating and exchanging knowledge that is CO-produced”



of our work has a translational component so we have a lot of guides for practice that we have developed in conjunction with people who will use them. We work with various designers and we have a process of making sure that our final products are usable by its end users. You can see them here <https://www.arts.unsw.edu.au/research/intellectual-disability-behaviour-support-program/resources/>

The strategic roadmap sets out where we see the future direction of research for this group. It shows what needs to change in our systems, in our policies and in our practices so that people with intellectual disability who have complex support needs have a system that properly supports them and a workforce that will be able to provide for those support needs. We see it as an important map in developing knowledge that is based in the lives of people and their experiences rather than what we think is a good idea for research.

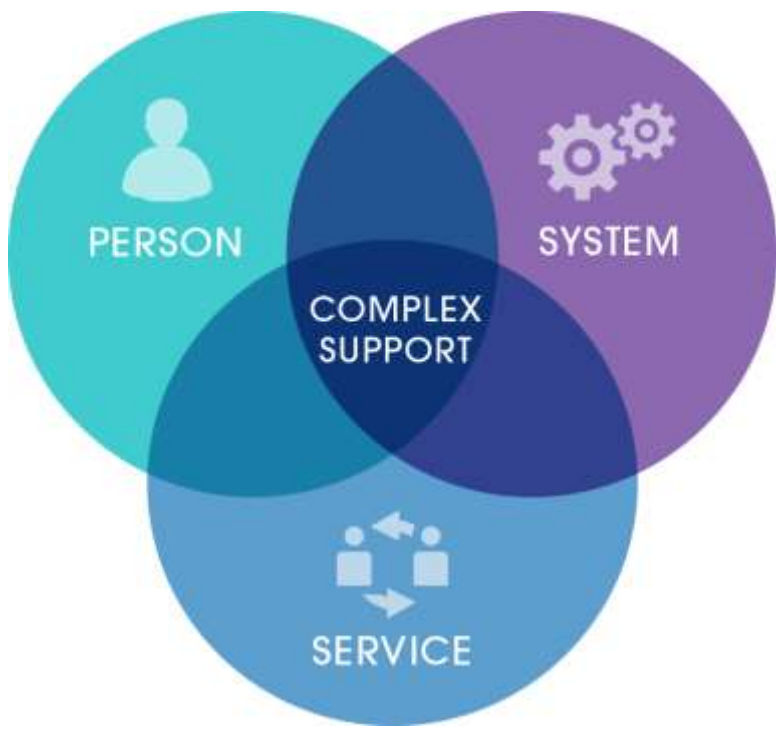
What are some of the challenges you face in your industry?

That's an interesting question - I work in the education industry within the university, and specifically in disability studies and research. I suppose the biggest challenge in the university context is that academics are under a lot of pressure to do all sorts of things and there is a big expectation from the community that academics should produce knowledge that is us-

able and that also it doesn't just use people as subjects of research but actually develops research that is needed by the community. As an academic there is a lot of pressure to publish, to get research money, to teach courses, to do a whole range of things which may not be in line with what the community thinks academics should do. So there is always a real challenge there between what the end users of research expect from researchers and what universities expect from researchers.

How can training help professionals support their clients or students?

Training is an incredibly important aspect of anybody's career development but I would say probably for me, it's not just about training but education. Education is bit of a broader idea where people come to understand not just how to do something or what to do, but *why* and how to evaluate, to challenge and to innovate. I think that's particularly important in disability where we are seeing all sorts of changes in the way that people with disability think about their supports and services. This requires us to think about what education really is. There is so much information around now about everything; you can Google just about anything. Understanding though, why you do something and being able to argue for why something is a good or a bad idea I think is absolutely key to professional practice.



Consultation and partnership is highlighted in your work, why is this important to you, your team and frontline professionals?

We take as our starting point ‘nothing about us, without us’, which is what people with disability demand from research. Our approach is never do any sort of research that doesn’t partner with people whose lived experience is the thing that we are exploring. Morally, we wouldn’t do research unless it was in partnership or very much in consultation with people. I think this has been a political shift; there has been such a long history of exploitation where research often caused damage or distress to people with disability. One of the things that we have to do first for our own professional ethics is to ensure that our work is co-produced and that it is addressing an issue that is important to people with disability as subjects of research.

What is your approach to working with complex patients who have complex support needs and an example of that approach?

We don’t talk about patients as complex; we talk about people who have complex support needs. The one thing I would say that is really important in terms of what informs our work is that we don’t think of the person as being complex. Instead we talk about complex support needs; the reason we do that is because complexity doesn’t reside in the person, a person may have multiple things happening, they might have multiple diagnoses, they may also have circumstantial

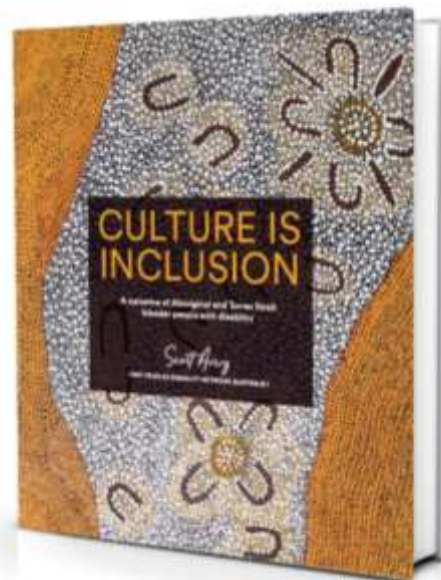
disadvantage, they may have a whole range of issues in their family, they may be socially disconnected and they may have experiences and needs for support which our service system itself is not able to support. When we talk about complex support needs we are really talking about the idea where a person with a set of needs, require support that a service system isn’t equipped to meet. The responsibility is not just on the person to be different, but the responsibility is on the service system to be responsive to the needs that the person has.

Those needs can never just be about impairment or diagnoses; they are always about the person in their social context, in their family context, with all of their strengths as well as the issues they need support with. We use this diagram to show how support needs arise at the intersection of the person; their service environment and the system that shapes what both do.

Image to the left is courtesy of Intellectual Disability Behaviour Support Program UNSW

Favourite book

I read quite broadly, both fiction and non-fiction, and my favourite book is usually whatever I am reading at the moment. Right now that is a most beautiful and important book called ‘Culture is Inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability’ by Scott Avery recently released by First People’s Disability Network. It is a culmination of several of years of intensive work and presents a narra-





tive of Aboriginal and Torres Strait Islander people with a disability. It's a ground breaking book with world first research and I recommend it to anyone with an interest in the experiences of our Aboriginal brothers and sisters with disability. The book is available on the FPDN website. <https://fpdn.org.au/product-category/publications/>

A web link you would like readers to see
IDBS website (image above and link below)
<https://www.arts.unsw.edu.au/idbs>

What do you take on holidays?

Probably not what but who - I always take my partner, I like to holiday in Italy and he can speak Italian.

Intellectual Disability Behaviour Support Program

Program Objectives

The Intellectual Disability Behaviour Support (IDBS) program works to address the research-to-policy-and-practice nexus to improve support for people with cognitive disability and complex support needs. The term 'cognitive disability' includes many labels - including intellectual disability, borderline intellectual disability, acquired brain injury and autism. Generally, having a cognitive disability

means that a person will have difficulty with things such as self-management, decision making and communication and experience some level of social exclusion.

The program achieves this through:

- Consulting with key stakeholders and developing collaborative relationships with academic, government and sector agencies both nationally and internationally;
- Leading the development and delivery of educational programs for frontline and managerial staff to support people with cognitive disability who have complex support needs and behaviours of concern;
- Leading a research program to inform support practices for those with cognitive disability and complex support needs across the disability and community sectors;
- Contributing to policy and practice approaches to cognitive disability support in alignment with international best practice;
- Focusing on areas where there is a specific need to address knowledge deficits within the Australian and international context; and
- Translating knowledge emerging from the IDBS program to ensure the work is informed by, and communicated to, a broad range of stakeholders.