

## conference keynote profile:

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In July 1992, as a clinical speech pathologist in a metropolitan intellectual disability service in Australia, I attended a group home in response to a referral from the House Manager to see a young man I will call 'Jamie'. The staff were concerned that Jamie had problems comprehending spoken language and seemed unable to understand when they told him to make his bed. Jamie had just turned 19. He had recently moved to the group home from his family home, had just finished school and had no other day activities. The staff reported their problem as Jamie not seeming to understand instructions to do simple tasks, him being unwilling to help with the daily tasks of the house and becoming aggressive if forced to do anything. They reasoned this was because he did not understand them and their aim was to get him to comprehend what they wanted him to do. They understood it was my job as the speech pathologist to teach him to comprehend and follow their requests.

When I asked where I could find Jamie, the staff revealed the unsettling information that he in fact sat in his small darkened bedroom all day, lashing out at anyone who tried to approach him. Back in my office at the end of that day, I pondered Jamie's predicament and listed all the factors that had culminated in the emergence of the 'communication problem' I had been called in to fix. These included social exclusion and isolation, lack of appropriate support, living in an institutional regime (dressed up as a suburban house with a very high fence), being a teenager, having nothing to do and being harangued

by staff insisting that he make his bed and do the washing up. This was all in the context of a difficulty understanding others and communicating in ways that they could or were prepared to understand.

I knew there was little I could do to change almost all of these things. I could try to work directly with Jamie to help him more 'appropriately' express his feelings, I could try working with the staff to develop some empathy and insight in an effort to make them better communication partners and supporters of Jamie or I could refer him to another arm of the professional team who were tasked with delivering the fledging approaches now associated with positive behaviour support. I knew however that none of these actions could begin to penetrate the complex web of material, social, political and cultural relations in which Jamie's life was embedded and through which he was marginalised and oppressed.

The experience of that day brought into focus a range of unsettling realisations about the ideologies, values and practices which made up the system in which Jamie, the group home staff and I found ourselves. It raised for me the question of how this oppressive control and ordering of life for people with intellectual disability could be challenged. I realised that the frameworks and processes of which we were part buttressed a system of repressive social management and cultural othering of Jamie. As simple as it sounds I realised that day that I was part of a problem and that I needed instead to be part of a solution. That realisation culminated in my pursuit, in the intervening twenty-five years, of

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a career focused on knowledge production with and about people with intellectual disability.

In the mid 1990s I was fortunate to work with a group of scholars at UNSW pioneering the introduction of what is now known as disability studies in Australia. This new field of inquiry began with the foundational recognition of a 'social model' of disability which gave me a framework to understand the clash between the individualising and pathologising approaches to disability embedded in our systems of social care and in our culture up to the that time, and opened up my thinking to the ways these embedded social relations could be challenged. The beginnings of the social model emerged from the experiences of disabled people in UK and North America, predominantly men with physical disability, and my PhD work, completed in 2007, was an early attempt at exploration of the barriers for people with intellectual disability in having their voices represented in 'social model' debates and more broadly in social and cultural responses to disability. Working with self-advocates in the UK and in Australia on the research project for my PhD set me on the path of inclusive and collaborative research with people with intellectual disability, an approach which is now, I'm happy to observe, widely embedded in the field of intellectual disability studies.

My experiences in disability research over the past twenty-five years have been diverse and perhaps best described as a journey in 'inter-disciplinarity'. For those of us working in the area of intellectual disability there can be no doubt that the lived experience is so much less about IQ scores or diagnostic labels, than it is about the complex ways that the presence of impairment opens up the lives of people with intellectual disability to complex social disadvantage

associated with poor service responses, vulnerability, poverty, violence, incarceration and social isolation. My current work as Chair in Intellectual Disability at UNSW focuses on an intersectional analysis that re-conceptualises this group of highly marginalised people in our society and promotes knowledge, policies and practices across disability and beyond to mainstream service provision which recognises their right to appropriate and responsive support from our social care system. As Australia's National Disability Insurance Scheme hurtles toward its full roll out in 2019, I am increasingly concerned that issues for this group are becoming caught up in the machinations of interface principles and arguments focused on cost shifting and service responsibilities across and between sectors.

As researchers, supporters and allies to people with intellectual disability we have come a long way since my experiences in 1992. Many people with intellectual disability undoubtedly enjoy much better lives in 2017, but my concern remains that without concerted attention and action we run the risk of re-inscribing a framework that sees those most marginalised cycle between out-of-home care as children, to hospitals, nursing homes and prisons as adults. These responses are fundamentally at odds with a human rights approach, assuming as they do that people's lives and support needs map neatly on to the currently silo-based service system. ASID has a significant role to play in this new landscape, and I am encouraged that there is now commitment to the use of this influence nationally in supporting calls for attention to ensuring that people with intellectual disability and complex support needs are not again left behind in the new disability services future. ●