

An interview with Professor Emerita Patricia O'Brien

On her retirement as Director of the Centre for Disability Studies affiliated with the University of Sydney.

Professor Emerita Patricia O'Brien PhD, FASID

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Tell us about your career and what some of the highlights of your career have been?

I started my career as a primary school teacher and then a special education teacher in the state of Victoria. I never worked in primary schools; I went straight into special education. From there I completed a degree at Monash University in the days when Monash University was “the farm”. It was the second university in the State of Victoria which initially was met with some scepticism! As a teacher I was fortunate to win a Rotary Teacher of the Handicapped Award which took me through to the University of Oregon where I completed a **Master’s in Education Degree in the late 70’s**. A program that I became aware of in the United States was called Citizen Advocacy (CA) where people with intellectual disability were matched on a one-to-one basis with community volunteers for advocacy and social connection. When I returned from the states, I gained a position as a lecturer at Victoria State College

(now Deakin University). It was at the time of the 1981, International Year for Disabled Persons and I won a competitive grant to set up the first citizen advocacy program in Victoria. At the same time, I enrolled at the University of Queensland for my PHD exploring the development, maintenance, and efficacy of Citizen Advocacy.

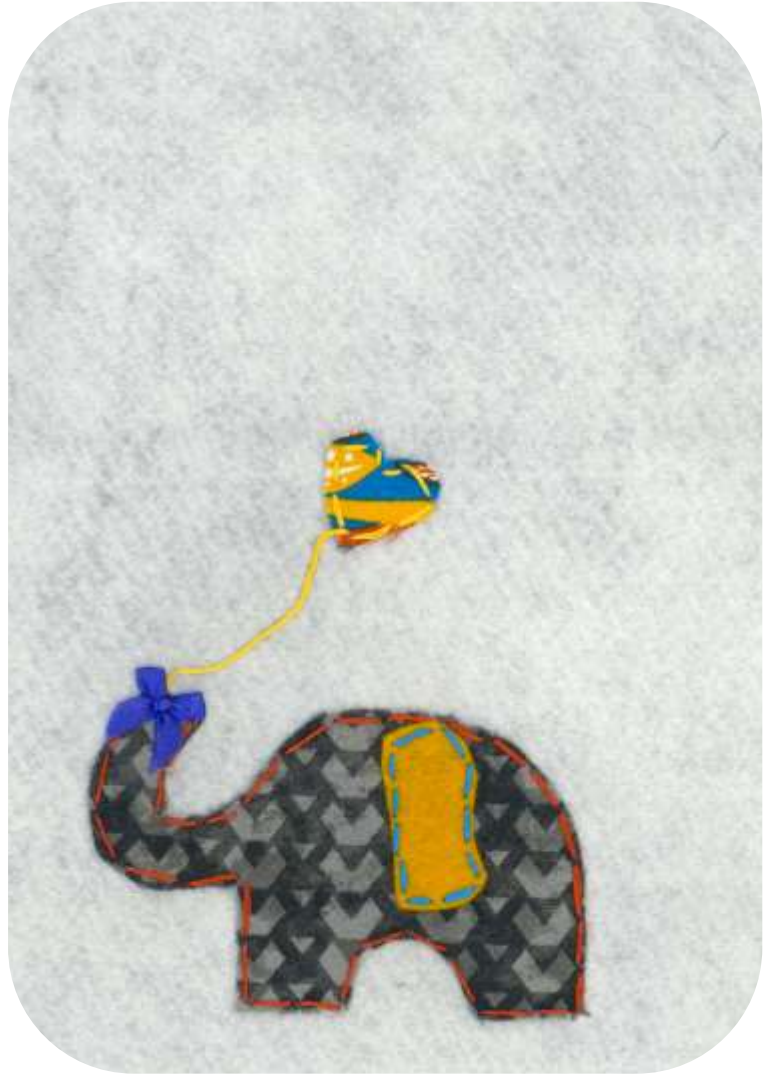
At Victoria State College I was teaching graduate teachers who were doing a Diploma in Mental Retarda-

“Trinity was an amazing place, built in 1592 by Queen Elizabeth 1st and its ancient history...”

tion! The students became the citizen advocates. CA programs then started to spread throughout Australia. It was at this time that I was invited to speak about the program at a conference in Auckland New Zealand where I met my husband, Ray who was widowed with three children. We married in Melbourne in 1985 and then I went to live in New Zealand rather than disrupt the lives of the children further. When I arrived in **Auckland I enquired about university or teacher's college positions and the response would often be, "I think you should contact Ray Murray who works in that area at Auckland Teachers College". I hesitated to say that I had just married him!** Ray ran the Centre for Special Education. I eventually would join the staff there but initially started to work for IHC New Zealand (Inc) where I led a devolution project to bring people with intellectual disability out of two long-stay institutions. It was one of the first devolution projects in New Zealand. To get out to one of the hospitals as a team we travelled off the highway north of Auckland down a long road that the families we meet named as *the road to Calvary*. The wildflowers that grew on the side of the road did not soften the pain of separation aroused through visiting the institution regardless of all its turrets and gargoyles and manicured grounds. The picturesque entrance to the hospital shielded from

view the stark dormitories where their sons and daughters had lived out a lifetime. Across the two hospitals we brought out over 120 people to live in the community and this would be one of the most significant projects of my career. We became aware of lives that had been wasted, where many people had not **retained their teeth, didn't wear undergarments, for fear that they would be discarded into the toilet bowls damaging the plumbing system of the institution.** The degradation of the people was visible and still memorable. Seven years later, by which time I was working at Auckland College of Education I won a Health Research Council Grant to follow up on the lives of these people which showed increases in their quality of life. Some people speaking after years of silence and experiencing the delight of having both their own bedroom and their own clothes rather than selected by staff from the dormitory clothing pool.

Another area of satisfaction from that time at Auckland College of Education (ACE), was co-developing the first degree for New Zealand in Human Services. I then moved into a position of Dean of Postgraduate Studies and Research at ACE in preparation for the transfer of the Teachers College into the University of Auckland.





Second in from right after CDS receiving a National Disability Award for uni 2 beyond presented by Dylan Alcott. 2017.



Opening the CDS Festival of Inclusion held at University of Sydney in 2019



Patricia in top right hand corner with the CDS Inclusive Research Group at 2019 ASID Conference

In 2001 our first grandchild Evie was born in England with Rett Syndrome. To be closer to the family I looked for a position in Europe and was fortunate to win the Foundation Directorship of the National Institute for Intellectual Disability (NIID) at Trinity College Dublin, which enabled us to travel frequently across the English Channel to watch and support Evie grow and thrive. Trinity College was built in 1592 by Queen Elizabeth

1st and with its ancient architecture and customs was a magical place to be for five years. In setting up the Institute one of the major advances for people with intellectual disability came about by developing the first accredited qualification in a university across Europe for people with intellectual disability. Living in Europe also opened opportunities for winning EU research grants, with a major achievement being that of a Marie Curie Grant to explore inclusive research for and with people with intellectual disabilities and their family members. The legacy of this work can be seen in the inclusive research networks found across Ireland today.

I had about a year left on my Trinity contract and was preparing to go back to New Zealand, when I received a telephone call from Sydney University recruitment asking whether I would be interested in looking at the Directorship of the Centre for Disability Studies (CDS). I was sitting with the chairperson of the NIID Board at the time and asked the caller if they could phone back. The rest is history. Ray had never lived in Australia before but was happy to delay returning to New Zealand. We arrived in Sydney in blistering heat in December 2009. It was a great privilege to take over CDS from Professor Trevor Parmenter, leading to 11 years of guiding and sustaining the Centre in its mission of “Building Capacity for Change” until my retirement in September 2020.

Which country have you enjoyed the most?

Wherever I am I like the most at the time. New Zealand is a fantastic bi-cultural place to live, landscape is magnificent, people are warm, considerate and inventive. It is also a great place for recognition of the voice of women. I was there for 20 years where at one stage the prime minister, the governor general, the attorney general were all women.

For both Ray and I going to Ireland was getting in touch with our roots. **I didn't have any known relatives still living in Ireland, but Ray did in the North whose hospitality we benefitted from.** My relatives came from the South around Clare and Ennis. As a member of **the O'Brien clan, I could have stayed on in Ireland but I am glad that I have returned to Australia made home by the courage of my forebearers crossing “the seven seas”.** I didn't think Ray would want to move countries as I did to New Zealand, but he is happy here, two of the adult children live in England and one in New Zealand so we move between all three.

What has influenced your work?

I think theoretically, Wolf Wolfensberger and his theory of social role valorization (normalisation). Similarly, the work of Burton Blatt who worked with Wolfens-

berger and coined the phrase: 'All people are valuable', which has become a mantra for me and Ray. I have had a long career and have lived through many stages and shades of theoretical development positioned to achieve better lives for people with disabilities. The seminal work of Michael Oliver and other social theorists continue to impact my thinking as does that of my **colleague and friend John O'Brien whose five accomplishments** set the scene for person centredness. In terms of other influences, my parents who spent their free time doing charity work, particularly for a palliative care hospice in Melbourne; the Brigidine nuns who were strong role models teaching and preparing us as young women to grow into our own independence; the commitment of my colleagues across several countries as well as the courage of many women and men that I have met who survived institutionalisation to lead valued lives.

The History and Future of the Centre for Disability Studies (CDS)

CDS started off in 1997 and has been running for over 23 years. Professor Emeritus Trevor Parmenter was the Foundation Director, followed by myself in 2009 and in 2020 I was pleased to hand over the Directorship to Associate Professor **Mary-Ann O'Donovan** coincidentally also from Trinity College Dublin.

The baton of promoting research, training and clinical services has been passed from one director to the next enabling the skilled and committed staff of CDS to support people with disabilities to vision and live the lives of their own self-determination.

While you were in the leadership role at CDS what was its most important work?

I could outline different projects, but I really think its most important work on my watch was around programs that impacted and positively influenced the way of being and life for people with disability, their supporters, carers, and professionals. There was a whole raft of flagship programs and innovations that looked to supporting people with intellectual disability to become more self-determining, such as inclusive research, the *uni to beyond* program where students with an intellectual disability are going to university, impacting both their confidence and self-esteem. When I first arrived, Ray and I had done a lot of work in Ireland on person centredness and so we continued that at CDS with colleagues such as Rachel Dickson and developed and delivered packages for NGOs across NSW that intensely trained staff, people with disabilities and management boards on what it meant to be person centred. Whether the programs were associated with research /training contracts on quality of



life, *Active Support* or the *I Can* support needs assessment tool, etc., it always came down to being guided by, how could we do it in a way that the findings and or training outcomes could be translated into meaningful and positive action for people with disability.

How can post school educational settings provide opportunities for participation for people with intellectual and developmental disabilities?

Such opportunities can come through co-design where people with intellectual disabilities join curriculum committees. This occurred for both the post school programs that I have been instrumental in setting up both at Trinity College Dublin and later at the University of Sydney. The two programs differed in that the one at Trinity enrolled the students into an accredited certificate where most modules although taught within the university setting were only delivered to people with intellectual disabilities. It was a hybrid model whereas by the time I arrived at Sydney my thinking had moved to the benefits of the students attending classes of interest with same aged peers as part of a fully inclusive model. Sydney university has welcomed students to sit in mainstream classes supported by peer mentors undertaking the same subject. Sydney University could not have been more welcoming of students with intellectual disabilities reflecting the leadership and positive attitudes by both its man-

“So I think CDS is a meeting place where people can gain information through research...”

agement and the student body. What would assist these types of programs to grow across universities would be that they are subsidized by government funding. NDIS packages can support the needs of students to attend but the co-ordination of such programs requires more accessible resourcing. In Alberta Canada, the government directly funds the co-ordination of such programs for students with intellectual disabilities who do not usually have the entry level qualifications that can bring resource subsidies.

What are the most significant advances in opportunity for people with ID that you have seen in your career?

In looking back over my career, the major changes include the closure of long stay institutions, which initially led to the development of group homes. Over the decades these have now been recognised as a potential form of institutionalisation, so more recently through the adoption of person centred thinking the concept of individualised supported living is growing in



Patricia in middle preparing to go onto ABC Radio program with two uni 2 beyond students

acceptance. When I started my career *education for all* was not part of the landscape so the right to education for all students regardless of their level of disability has been most significant. Similarly, the recognition of people with disability being self-determining in directing the quality of their own lives has gained acceptance as illustrated in the UN Convention of the Rights of Persons with Disabilities that Australia has ratified. The role of people with intellectual disabilities **as no longer “being the researched” but “doing the research” has also been recognised.** An area that continues however to be a concern is that of social isolation and lack of community participation. Being present in the community does not necessarily mean being accepted for who you are. The NDIA has started to make a difference here with people being able to be funded for choice of activities. Ongoing advocacy will be needed however to keep the funding and attitudinal flame burning.

Favourite app

WhatsApp is playing a huge role in our COVID lives. Having the family in 3 different countries, we are using WhatsApp to communicate frequently. We are getting a lot of pleasure from picking up regular group messages.

Favourite book

Brideshead Revisited (The Sacred and Profane Memories of Captain Charles Ryder) by Evelyn Waugh. There was also a television series and a movie. Evelyn Waugh was an English journalist and wrote a lot in and around the Second World War. This book is about an aristocratic family that live in the UK. They invite into their family a student from Oxford named Charles Ryder and he falls in love with the older daughter. I really like the grandeur, set around the towers of Oxford but intertwined with the issue being faced by the major protagonists that the Catholic Church did not condone divorce which also reflects the pain of the era I grew up in. Other books I enjoy are those of the Bloomsbury set, people like Virginia Woolf. Travelling to and from England regularly to see our family we would often stay in Bloomsbury and walk the squares familiar to those authors.

What do you always take on holidays?

Too many clothes! We were once on a train going into Paris from Charles de Gaulle airport and a woman helped us struggle into the carriage with our luggage. **She asked “Are you moving countries!! Or at the Cologne railway station where a friend came to pick us up and was stopped by a passer-by who asked if he could take a photo of us as with our two trollies of luggage as he was doing an assignment of people and luggage! Our excuse is that we are always loaded with gifts for family when we travel to England in particular!!**



Screen Shot 2019 Graduation Ceremony , University of Sydney

Finally, will you be keeping your interest in the welfare of people with ID active in retirement?

Retirement will give me chance to give back through Board work, writing and continuing to support others to research in the area of disability studies that has given me so much across my career.

Further reading

O'Brien, P., Bonati, M. (2019). From Institutionalisation to Inclusion. In Patricia O'Brien, Michelle L. Bonati, Friederike Gadow, Roger Slee (Eds.), *People with Intellectual Disability Experiencing University Life: Theoretical Underpinnings, Evidence and Lived Experience*, (pp. 3-19). Leiden: Koninklijke Brill NV

O'Brien, P. (2020). "No researching about us without us as decision makers." Commentary on "Are individuals with intellectual and developmental disabilities included in research? A review of the literature" (Jones, Ben-David, & Hole, 2020). *Research and Practice in Intellectual and Developmental Disabilities*, 7(2), 120-125

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