



This transcript of VALID's Podcast, an interview with John McKenna and Professor Gerard Quinn has been provided by Deakin University for educational purposes.

JOHN MCKENNA:

Hi there, John McKenna with another VALID Podcast. You're about to listen to an interview I did with Professor Gerard Quinn from the National University of Ireland who is acknowledged as a world-leading authority on International Disability Law. Gerard was instrumental in the development of the UN Convention on the Rights of Persons with Disabilities.

He was recently invited to Australia in March 2019 by Deakin University to do a series of presentations. During his visit, I was able to meet with him and have a great chat. It was really interesting to hear how other countries are looking at topics such as guardianship, supported decision making, and how other countries are also closely looking at the development of our National Disability Insurance Scheme. The podcast goes for about 10 minutes.

Hi I'm John McKenna and welcome to the VALID Podcast. I'm with Professor Gerard Quinn. Good day, Gerard.

GERARD QUINN:

Hi, how are you doing?

JOHN MCKENNA:

Tell us your story.

GERARD QUINN:

Well, I started life as somebody really interested in legal history and legal change. And all that changed very dramatically for my wife and I when our first daughter was born with a disability in late 1989. And just a few months later, I was watching TV and so President Bush number one sign into law the Americans With Disabilities Act, and said to myself, "You know what? We can do that here too." Meaning in Europe.

JOHN MCKENNA:

OK.

GERARD QUINN:

So, the rest is history since then.



JOHN MCKENNA:

That's a nice story.

GERARD QUINN:

Yeah. And you can trace it right back to that moment.

JOHN MCKENNA:

It's a lovely story. I guess we're really interested in having you as part of this podcast, you've got a real global perspective on things you've seen in different countries. So, let's get straight to the heart. A big issue for people in Australia especially is different types of supported decision making. What would you like to share with the whole world right now what you've seen and how it works?

GERARD QUINN:

Well, I think if you zoom out from the actual application, what's at stake really is a completely different way of looking at personhood, a completely different way of not objectifying people and treating them as subjects in their own life. And then once you follow the logic of that, so much change is needed, not just to centre people in their own lives, but to press the reset button with respect to people who are in their lives like service providers and indeed to enable them have just not just individual voice, but collective voice in the political process. So, it's that whole dynamic of change that I'm really interested in.

JOHN MCKENNA:

It is. But it's also is it fair to say when we talk about carers and family members, how do we take them on that journey?

GERARD QUINN:

Oh, it's really hard because the whole service system right around the world especially actually in richer countries has grown to gigantic proportions as a momentum all of its own. And you can change a lot at the level of legislation and rhetoric, but changing those institutionalized practices around that's going to take a generation I reckon. But we're kind of headed on the right journey, maybe faster in some countries than in others. But then it is the big challenge.

JOHN MCKENNA:

So, Gerard, you're lawyer. So, looking through the legal lens, are lawyers getting it, are the legal systems getting it? And if so, which country's got the lead?



GERARD QUINN:

I think, you know, we can do a lot of change at the superficial level of law, but deep down the legal culture hasn't really changed. Deep down legal culture is very comfortable continuing to objectify people and not very comfortable with moving to viewing people with disabilities as subjects, autonomous beings, exercising moral agency in their own lives. I don't think any legal culture in the world has yet caught up with, for example, the UN Convention.

And it's a long term change. It's not something that's going to happen overnight. I would point to one or two countries that are kind of in the lead. Maybe surprisingly, Israel is doing quite a bit on supported decision making some new legislation. Peru as you know has abolished guardianship altogether.

JOHN MCKENNA:

Any good examples from Israel that you can share?

GERARD QUINN:

Well, it's fascinating that the legislation started out or otherwise motivated by some court cases that individuals brought demanding that guardianship not be imposed and that some least restrictive alternative like supported decision making would be imposed. And the courts agreed and that then led to a project in the legislature to bring about supported decision making for everybody without a court intervention which is quite fascinating.

JOHN MCKENNA:

How quick have you learnt about our National Disability Insurance Scheme in Australia?

GERARD QUINN:

I was attentive to it a few years ago when it started out. I spent some time in UNSW in Sydney about three years ago. I was quite fascinated by it. And the reason I was fascinated by it is because there is an article in the Convention that basically requires services to be personalized to the individual, personal assistance services but also other services. And you know there's a trend around the world of individualizing budgets, enabling people exercise choice. So, Australia was really quick out of the stops in actually trying to implement this at the level of ideas.

JOHN MCKENNA:

I see.

GERARD QUINN:



Since then, I'm not quite sure how it's panned out in practice, but a lot of people around the world are really interested in the experience because they're only beginning now.

JOHN MCKENNA:

OK. And that still comes back to types of decisions that are made at planning meetings.

GERARD QUINN:

Yes.

JOHN MCKENNA:

Which is a real challenge for, you know, it's alright to have someone with, you know, a person such as myself with a physical disability for the... But for the person who is nonverbal, how are they standing up and how are they getting the message?

GERARD QUINN:

Well, I read a great PhD from the University of Sydney which was a critique of the voice or the lack of voice of people with intellectual disabilities in those meetings to do all the various planning. It was fascinating piece of work.

JOHN MCKENNA:

OK.

GERARD QUINN:

And what she was basically advocating for was a more nuanced concept of supported decision making to enable people, especially against the backdrop of family members, to exercise their own voice and to have some say in the process.

JOHN MCKENNA:

I see. So, you're gonna go back to Ireland I guess after your trip. It's where home is for you?

GERARD QUINN:

That's home. But I actually have to research chores out of Ireland. One is in Sweden, the Raoul Wallenberg Institute, which does a lot of work in China which I'm very, very happy with.



JOHN MCKENNA:

Right.

GERARD QUINN:

And the other is the University of Leeds in the UK which is one of the original centres for disability studies in the world.

JOHN MCKENNA:

So, it's interesting I keep coming back to decision making. Are you able to perhaps give us a couple of gold roles that you'd like to pass on to a family member or even someone with an intellectual disability, how do they stay strong knowing that legislation is such a big animal to fight? How to people stay strong to keep going?

GERARD QUINN:

Well, I think there is one big message from the UN Convention which is that you're not an object. You're not even an intermediate object, what they call persons of lesser moral worth. Believe it or not, that is a title within ethics.

JOHN MCKENNA:

Is it really?

GERARD QUINN:

Yes, absolutely. You are a person and you are a subject in your own right and you're quite entitled to exert yourself in the world and to make your views known. Otherwise, you're prey to the depredations of third parties, well-intentioned or otherwise. That is the big message of the UN Convention. It's all about taking the cloak of invisibility away from people, restoring them power over their own lives, and then dealing with the consequences of after that which is, for example, rolling back the way services have done delivery in the past.

And that's a generational task, but it is heading in the right direction I think. We have an association of service providers for people with disabilities at European level. And they actually get us and their slogan now is, "We've brought people to disabilities in the past. Now we need to bring services to people with disabilities where they are in their own lives."

JOHN MCKENNA:

Wow, that's beautiful.



GERARD QUINN:

Yeah.

JOHN MCKENNA:

Gerard, thank you very much for joining me on the VALID Podcast.

GERARD QUINN:

You're very welcome. And I'm going to continue to be interested in how Australia evolves.

JOHN MCKENNA:

Thank you.

GERARD QUINN:

Yeah.

JOHN MCKENNA:

We hope you enjoyed the VALID Podcast. For more details about VALID, please have a look at our website [www.valid.org.au](http://www.valid.org.au).