

# interview with professor Eric Emerson...

## Interview with Professor Eric Emerson

*Eric Emerson is Professor of Disability Population Health at the Centre for Disability Research and Policy at the University of Sydney and Professor of Disability and Health Research at the Centre for Disability Research at Lancaster University in the UK. Professor Emerson is an active researcher in the field of intellectual disabilities (learning disabilities). He previously held appointments at the University of Manchester, University of Sydney, University of Kent at Canterbury and in a range of health care organisations in the UK and Canada.*

*His current research interests include understanding the social, cultural and economic bases of the health and social inequalities faced by disabled children, their families and adults with intellectual or developmental disabilities. Building resilience among and improving the physical and mental health of disabled children, their families and adults with intellectual/developmental disabilities. Policy and practice relating to disabled children, their families and adults with intellectual/developmental disabilities. Disability in low and middle income economies.*

*Below is a candid interview with Professor Emerson that gives us some insight into one of the great minds of research in intellectual disability.*

### How did you start working in the field of Intellectual Disability?

I went to see if there was a nursing assistant appointment nearby as I had worked a bit as a nursing assistant, but they didn't have any jobs at the time but they told me that across the road was a mental handicap hospital who were looking for an assistant psychologist so I just popped along and they gave me a job, it was pure chance.

### What type of clients were you seeing to begin with?

When I was working in that hospital it was a range of people including for example people with severe self-injury. Then when I trained as a clinical psychologist I worked in mental health services for a bit then went back into intellectual disability and began to work more and more with people with challenging behaviour, I guess I just got interested in the area and began to specialise in that area.

### What piece of work influenced your career?

It would be the work of the early behaviourists, without a doubt. It is difficult to think about how different things were in those days but the radical new ideas that were coming out were actually showing that people with very severe intellectual disability could change. There was huge potential there, that could be tapped if we did things right. Doing things right was getting the environment right and getting the support right. That was a radical departure from the way people were thinking

---

**“Both countries are moving heavily towards a model of disability provision which devolves more and more power to families and individuals...”**

---

before, that this was all inevitable, biological, driven by internal pathology and disease. So there is this group of people saying well actually it is nothing to do with that (perhaps overstating the argument), they did some fantastic work in the early days in the 60s and early 70s kind of demonstrating what potential for change there might be among people that society might have completely written off, and that was very influential and I became a card carrier for behaviour analysts for a decade or so.

### What about your own work? What piece of work do you think may have changed your career?

It would be two, or three things really. One was an opportunity to work with Jim Mansell at the Tizard Centre, I don't know whether you have heard, but he sadly died recently after fighting cancer for a number of years. That opportunity to work with Jim for three years when we set up a kind of specialist advisory consultancy service in the southeast of England specifically working with the most challenging people we could find, which was certainly a remarkable opportunity which certainly changed my career path completely and led on to writing books on challenging behaviour and that kind of stuff. The other thing that probably changed things was after I left Tizard Centre and went to a

research centre in Manchester we did lots of work for the government looking at the quality and costs of supported accommodation services and that had pretty profound impact on the way services are being provided certainly in the UK with the closure of what were becoming the new institutions. I think the third big change was coming over to Australia in 2003/2004 where I spent five months working with Trevor Parmenter and that was on sabbatical, which was the first time I had ever had the opportunity to get away from the daily job sit back and think about what was going on and that's the time in which is discovered that this whole different world and way of thinking about things which are the social determinants of health and that certainly has had a major impact on what I have done so far.

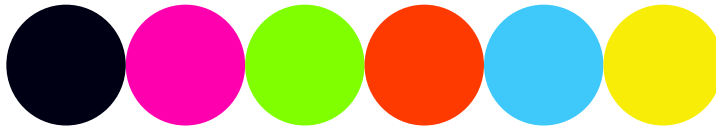
### What do you enjoy about your connections with Australia?

I would like to say the sunshine, but not this summer. It's a number of things, the culture, a much better work-life balance that people have over here (I know people complain, go to the UK and see there is a difference).

There is a very European way of looking at things which tends to complicate matters. It is like we are weighed down by history; in a living crypt we are surrounded by a three hundred year old building you are continually reminded of history, repetitions of history and how difficult it is to change things. The Americans are completely opposite, they don't seem to have a clue and think you can change things at the drop of a hat and both extremes have their problems but I quite like that in Australia there seems to be a happy middle, where they meet somewhere in the middle of that. There isn't that cynicism that pervades a lot of discussions in the UK but neither is there a naive belief that you can change things that you pick up from many North Americans. So I think there is a happy medium there and also the way people approach life, and their jobs, and I really like working at the University of Sydney. It is just a really good place to work.

### With your international perspective, how do you feel services fair for people with intellectual disability in comparison with the UK?

I think it is really hard to answer that question because what is clear if you look at either of those countries is just the



massive variability in the quality and what is provided. I think both countries share a common problem in that they don't have enough services. So there are lots of families out there in particular receiving very little or no support who we really should be supporting. They ought to have a right to descent quality support. I think that is something the two countries have in common, pretty much at the same level I think. I don't see a great difference there.

There is a difference to an extent in the types of accommodation services that we provide in that we as an English government decided that cluster housing was really not going to be provided in England and so all people providing cluster housing are having to close them down while at the same time in NSW they are opening them so there is some differences there but of course that varies from state to state and if you try to summarise across Australia it is like trying to summarise across England, there is such variability depending on which state you live in but also which local authority you live in, it is really difficult to try to get the big picture.

The big picture is one of variability and overall insufficient investment in services and support.

There are a lot of things they have in common. I think both countries are moving heavily towards a model of disability provision which devolves more and more power to families and individuals, I think that is generally a good thing as long as it is done well. Both countries having the same aspirations of social inclusion for people with disability and that is definitely to be welcomed. But both countries are finding a way of doing it.

Everywhere still has a lot of work to do, there is no green grass over the hill I'm afraid, despite what the Americans say, because having worked in North America, the difference between the reality of what's on the ground and the rhetoric you hear when Americans are speaking at conferences is just huge. Like everywhere there are some really good programs and really good examples but when you look at the routine provision; that is a different matter

#### **What do you think is the biggest challenge for people with intellectual disability?**

I think the biggest challenge is the discriminatory and disablist attitudes which pervade society in which they live in. They are people with such low social status who really don't count, and that's their biggest problem; all the other things tend to flow



from that, they don't get support and are just rather ignored, they politically just don't count and are generally looked down upon as being less than human. Why on earth do we invest in money to allow parents to abort fetuses with Down Syndrome if we don't believe that they are not worth it?

#### **What changes to the quality of life of people with intellectual disability have you seen over your career?**

Huge changes in things like the quality of out of home living environments we provide.

I started in the mental handicap hospital that was a large institution but at the same time we had these huge Victorian institutions but if you look at the quality of the living environment it has changed out of all recognition. It is still not good enough but compared with where we were 35 years ago there is just this huge change. And I think, certainly in the UK for the time being, we have won the argument that you don't need institutional provision; that has been a long battle. That has been a major change. Just that leap within policy in professional communities that if you have anything that looks institutional it's our problem, not because someone with intellectual disability needs that kind of service, it's just that core providers are providing the wrong services.

There are clear changes in the extent to which there is an expectation that people with intellectual disabilities will effectively participate in the way things are developed and run. They have a contribution to make. Of course when you look at the power that people actually have, that is a different matter.

#### **Do you have areas of optimism or caution for progress in the social, health and welfare of people with intellectual disability in Australia?**

I think the optimism has to be that Australia has a higher policy level which has clearly committed itself to social inclusion and personalised supports for people with intellectual disability and that is worth an awful lot. Having that policy is not going to make things happen but if you don't have that clear vision at the top things are much harder to happen. I think that causes great optimism.

I guess the caution is how to deliver that and I think we need to be careful about how we enable some of this to work through the use of individualised funding and individualised budget and personalised funding support etc. because one of the lessons from social policy intervention which have tried to devolve power down to the individuals and families is that some families are better equipped to take ad-

vantage of those opportunities than other families. So it can be quite devious and often the people who benefit most from that are the more articulate middle class families who know how to work systems and so families who are struggling financially, living in poor communities or don't have any supports could be left behind with these resources. It is not inevitable but needs some careful thinking about what you need to put into place to make sure that those families who are going to need additional support, get that additional support and they get it at a quality which is as good as those families who have those capabilities.

**In your view, how important is academic and scientific study to fostering changes of life circumstances for people with intellectual disability?**

I wouldn't overstate it. It can be influential; there is no doubt about that but you need a support of a policy environment for it to be effective. For example, we did a major study on the quality of cluster housing in England and that was used by the government to order the closure of all cluster housing in England. It was influential because it supported the policy direction that the government wanted to go in. It didn't create that mind shift but it allowed people to act and they could go on and argue to their ministers, look, we have the evidence that this is the right thing to do. So it can be very important in those kinds of ways. Similarly, we have just instituted annual

health checks for all adults with intellectual disabilities. We would not have been able to do that without the work of people like Nick Lennox in Queensland. So it can be important, those kind of technical bit of evidence can enable things to happen. They don't make things happen, but enable them. But I think what is more important is the ideas that come from academic work, for example the work of the behaviourists, just changing ideas about what is possible. It was challenging basic ideas rather than providing evidence, it was showing what could be done. I think it is the power of ideas, rather than evidence in a way. Goffman's early work on institutionalisation; incredibly influential. You look at the quality of what he did which wasn't that impressive but it was the idea that was influential.

**What was the last thing you read?**

Academic paper about employment transitions in the UK.

**What is your favourite book of all time?**

It would have to be an Ian McEwan book, not sure which one though.

**Something you like about your field of work?**

The variety, and just the intellectual challenges. It is like being a detective all the time. Trying to figure out what is happening. Even after all these years trying to

figure out what does this data mean.

**A web-link you would like to share**  
[www.equalitytrust.org.uk](http://www.equalitytrust.org.uk)

**Current Project**

In the UK, I don't really do research anymore; I am co-director of a population health information unit on intellectual disability. So we provide a government service.

In Australia we are looking at the transitions in and out of disability across the life course, it is not specifically about intellectual disability anymore, it is more disability broadly. We have just finished some work looking at level of disadvantage faced by children in Laos, Bangladesh, Cambodia and Thailand.

**Mental Health and Intellectual Disability in the future what do you see:**

I see greater attention being paid to issues of prevention and thinking about this more as a public health issue rather than a clinical issue. I think that is happening already and is in the air internationally.

I would like to see the benefits of the ideas that we have extended to low and middle income countries but I am not confident that will happen. ●

*Below: Left to Right, Associate Professor David Dossetor, Associate Professor Eric Emerson, School-Link Coordinator Jodie Caruana*

