

## **Disbanding ‘disability’ and opening the door on difference**

### **An interview with Professor Gwynnyth Llewellyn, Dean of the Faculty of Health Sciences**

People with disabilities cannot access appropriate services and support to enable them to participate in society due to the innate prejudice and discrimination in our society, argues Professor Gwynnyth Llewellyn, Dean of the Faculty of Health Sciences.

‘With around 15 per cent of the population with a disability, it’s about time we started seeing ‘disability’ as normal but with a difference. Disability comes from being excluded by environments that do not accommodate difference,’ she said.

‘I would like to see the concept of ‘disablism’ high on the public agenda – like racism, it needs to be viewed as unacceptable.’

Professor Llewellyn’s groundbreaking body of research explores the experiences of people with a disability and their families and highlights conditions that restrict identity and prevent families and individuals from controlling and planning their own lives. Her work has raised awareness of the needs and issues of people with a disability and their families, and led to improvements in professional practice and government policy in this area.

Professor Llewellyn is the Director of the Australian Family and Disability Studies Research Collaboration (AFDSRC), established by a team of academics and researchers within the University to identify, promote and address the issues faced by families with special needs. ‘Through the dissemination of knowledge derived from our research, the AFDSRC aims to bring about change to overturn the discrimination of people with disabilities,’ said Professor Llewellyn.

Since 2005 Professor Llewellyn and her AFDSRC team, in partnership with the Parenting Research Centre (Melbourne), has developed and implemented a major national strategy to provide support for parents with intellectual disabilities and the services that work with them. This *Healthy Start* initiative ([www.healthystart.net.au](http://www.healthystart.net.au)) is funded by the Australian Government, under the Stronger Families and Communities Strategy. The strategy aimed to provide appropriate education and support to parents with an intellectual disability, enabling them to create a safer, more supportive environment for their children.

Thus far the *Healthy Start* initiative has used various strategies to successfully build capacity and support the adoption of evidence based practice by practitioners working parents with intellectual disabilities. Such strategies have included the development of local leadership and cross agency collaboration, training practitioners in evidence based parent education programs, provision of web based resources and communication, graduate education opportunities and the trial of two innovative practitioner resources.

Professor Llewellyn has also extensively researched the experiences and insights of older parent carers of children with disabilities, with co-researchers Professors Lindsay Gething, Hal Kendig and Rosemary Cant.

Based on interviews with 64 older parent carers, their findings reveal the heavy toll of decades of caring for a child with a disability. 'Older parents cannot continue caring for their children indefinitely. They get worn out after 20, 30, 40 years of caring. It takes its toll – physically, psychologically and economically,' said Professor Llewellyn.

The research found that older parents caring for adult children with disabilities are not receiving the support and services they require. They are being let down by a service system that does not understand their issues and needs.

The knowledge and evidence gained from this research will inform government policy, service development and professional practices. For example, it has contributed to the expansion of the Carers' Branch of the Commonwealth Department of Health and Ageing and the formation of a National Strategy for Carers.

Professor Llewellyn has plans to expand this research, exploring the issues and needs of parent carers of people with a short-term disability.

Also on the agenda is addressing the needs and issues of sibling carers. As parent carers get older, siblings are required to step in and take over the carer role. 'It's a very neglected area,' she said.

Professor Llewellyn's innovative study on parents with an intellectual disability in the early 1990s highlighted the damaging stereotypes and lack of community support that was isolating these families. The research showed that when parents with a disability get early access to support their children are also likely to do well.

'A decade ago services acted like parents with a disability just didn't exist. It was thought they had no right to have a child. Parenting services wouldn't touch parents with disabilities because they said they didn't have expertise in this area, and disability services said they didn't know anything about parenting.'

'A great achievement is that services now feel responsible to provide services for parents with disability and government policy dictates that they can't discriminate against someone because of disability.'

Professor Llewellyn believes the key to attracting post graduate students to the disability area is to share her own knowledge and passion and allow people to be inspired, 'if that is their inclination'.

'I try to make myself available and I encourage my colleagues to share their insights and experiences with students where possible.'

Professor Llewellyn currently serves as a Ministerial appointee on disability to the Children's Court Advisory Committee; NSW Disability Research and Development Group; Department of Community Services Research Advisory Council; and, a Director of the Royal Rehabilitation Centre, Sydney.

She explained her roles in informal advocacy – including advisory work for Legal Aid – are as important as these formal appointments.

'I regularly receive requests for information and support from research participants who ask for help. I try to be available to the community and share information, knowledge and expertise where I can.'

Professor Llewellyn's interest in the area of disability stems from her early career as an occupational therapist where she saw how discrimination was affecting the way services were delivered to people with disabilities. 'The lives of people with a disability were restricted not just by their impairment but by the lack of access to appropriate services. We were seeing intergenerational discrimination and disadvantage,' she said.

'I was inspired by a particular occupational therapist who said that if people like me didn't stand up against discrimination of people with disabilities they would be still languishing in institutions. I felt accountable. I felt I had to do something to combat discrimination.'

Professor Llewellyn has seen a lot of gains since these early days of her career. Her research has changed the way services perceive people with a disability and improved professional practice.

'My proudest achievement is that people with disability are now on the public agenda, whereas before they were closeted away – along with their families.'

| [Services now](#) see that they have a responsibility to provide appropriate services.'

But we still have a long way to go, according to Professor Llewellyn.

'The current situation is that when there is a child with a disability their family also becomes disabled because we do not accommodate their needs. They are put on the disability pathway where there is no light at the end of tunnel. They felt they cannot get off the treadmill of searching for services and they end up feeling very disadvantaged in our society.'

'My dream is that we change this.'