

Editorial

As we approach the second decade of the 21st century, the papers in this special issue look back at some significant years for people who have been labelled as having “mental health needs” or a “learning disability”. Historically, these are both labels that have been applied to people without a voice, people who need care, but who do not have an opinion that could be valuable. Yet, in 2007 the first guiding principle of the United Nations Convention on the Rights of Disabled People enshrined the notion of individual choice and autonomy, with these words:

Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons (UN, 2007)

Many years before the turn of the millennium, disabled people themselves led the way in re-thinking the very definition of disability (Oliver, 1990). The social model that they proposed effectively turned attention from what is wrong with the individual, and shifted our gaze to society. This includes all the practices that underpin our society, including family care, health services (such as mental health nursing, which is the focus of Lloyd's paper); research (the focus of papers by Marriott and Bollard); day care and drama (the focus of Charnley et al.). All these endeavours can be oppressive, but they can also be turned around to be enabling, if disabled people have a say in their development and are at the heart of their management. That is why the papers in this special issue are so important.

Models of participation are far easier to draft in theory, than to implement in practice. In my own experience, and that of my colleagues at Norah Fry Research Centre in Bristol (Walmsley & Johnson, 2003), there is no one 'ideal' way of including people with learning disabilities or mental health needs in research. That is an important point; the method needs to match the purpose. Moreover, by definition, these 'empowering' projects cannot just be the responsibility of professionals. Researchers, nurses, psychiatrists or drama therapists can only set the context for change; the rest has to be done by disabled people themselves.

Nevertheless, the original notion of emancipatory research (Oliver, 1992) was not about disabled people doing everything themselves, but was more about control and change; the practices discussed in this special issue share those goals. What all the papers have in common is that they turn around the traditional positions of nurse-patient; therapist-client; researcher-researched; service provider-service user. They attempt to redress the power balance at the heart of those relationships, and to ensure that the traditionally powerful professional can learn from, and be guided by, what disabled people want.

What will be most effective in enabling people with 'mental health' or 'learning disability' labels to influence change? These labels are applied to a vast range of different individuals, but both labels have been associated with a lack of competence and an inability to manage everyday life (Beart et al., 2005). Therefore, the fundamental change at the heart of all these papers must be a change of attitudes towards disabled people. This attitudinal shift is demonstrated in this issue by Heneage et al., who describe how an individual service user took part in professional training. Simply meeting and listening to a person who has lived experience of services, can be profoundly influential in enabling professionals to work on a basis of equality. The actors in "Full Circle" in Charnley's paper also challenged conventional wisdom, in escaping the confines of a day centre, and becoming professional actors and researchers. People with learning disabilities, as Gant's paper shows, can also become carers for their elderly relatives, despite the common assumption that a person with learning disabilities is naturally in need of care, rather than giving care.

The voices of disabled people are at the heart of all the papers in this issue, whether they are trainers, participants, carers, researchers or steering group members. However, a key criticism leveled at projects such as these is often that of tokenism (Chappell, 2000; Walmsley, 2001). Do disabled

people really have a voice, or are non-disabled professionals simply using them, to further their own ends? In order to be transparent about that question, we need to look in detail at the way people communicate with each other, on public platforms, training meetings, and in their everyday lives; I have made an attempt to demonstrate a way of doing this in a forthcoming book (Williams, 2011).

Partnership is the key to the type of work described in this volume. Most of these papers describe situations where people are working together. What becomes clear is that different levels of participation can be effective in different contexts. Where Bollard describes participation in a research steering group, Gant included people with learning disabilities as research participants, and Marriott enabled disabled people and their carers to be at the heart of an agenda-setting exercise, for future research. The challenge for these partnerships is to ensure that disabled people are equal partners; their voices will grow and develop, as their own sense of ownership becomes stronger. In practice, this may mean taking time for people to make a genuine contribution, giving good support, and being prepared to change and be challenged ourselves.

In reading the papers in this special issue, therefore, we need to bear in mind some of the challenges for the years ahead. For instance, how can people with 'mental health' or 'learning disability' labels really be supported to gain in strength and have more powerful voices? Particularly in times of financial stringency, how can we ensure that training and research projects really change practice, so that services and supports become more respectful of individual service users? And finally, what messages can we take away from these papers, in order to influence and gradually change the wider attitudes of people throughout the community?

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