The challenge of the Convention on the Rights of Persons with Disabilities to health and social care professionals

**The challenge**

Disability, and the necessary responses to it, are no longer understood in narrowly medical terms. Thanks largely to the growth of the disabled people’s movement, the role of physical, social and cultural environments is now known to be critical in the disability experience (Shakespeare 2006). The Convention on the Rights of Persons with Disabilities (UN 2006) outlines the human rights to which all people with disabilities are entitled, and mandates States parties and other duty holders to remove barriers in every aspect of life, including access to healthcare (Article 25).

Disabled people are a significant minority. It has been estimated that one billion people in the world, or 15% of the population, are living with disability (WHO 2011). Across the lifespan, approximately 5% of children, 10% of working age adults, and up to 50% of older people have health conditions associated with disability. For example, a recent study found that nearly 10% of women who gave birth in UK in 2000-2002 had life limiting illness (Sumilo et al 2012).

While disability is not simply a medical issue, people with disabilities do have health needs, both those arising from their primary impairment or illness, as well as the range of general health needs experienced by the non-disabled population, such as the need for immunization or sexual and reproductive healthcare (Shakespeare 2012). In addition, people with disabilities often experience a narrower margin of health (WHO 2011). This may arise because of vulnerability to secondary health conditions, such as pressure sores; because of co-morbidities, such as diabetes associated with schizophrenia; because of lifestyle, such as overweight associated with intellectual disabilities; or because of socio-economic deprivation.

Yet evidence shows that these general and specific health needs are not adequately met. Inadequate health system response to people with disabilities arises from a number of factors. Financial barriers to healthcare services are relevant in many settings. Physical accessibility of healthcare facilities – from buildings to examination couches – is another important barrier, together with distance to healthcare facilities and lack of accessible transport.

Moreover, a crucial role is played by the attitudes and practices of health professionals. Analysis of the World Health Survey showed that people with disabilities were twice as likely to find health care provider skills and equipment inadequate to meet their needs; three times as likely to be denied care; and four times as likely to be treated badly by health care providers (WHO 2011).

This evidence of the critical role of health professionals is reinforced by other studies. A large French study of GPs found that 21.3% reported discomfort when treating people with intellectual impairments or mental health conditions, and 8.2% when treating people with physical disabilities (Aulagnier et al 2005). Furthermore, a US survey found that 9.8% of physicians felt uncomfortable about treating people with Down syndrome (Pace et al 2011). Review of research about nurse attitudes to disabled children has found similar problems (Cervasio 2010).

Poor attitudes may often combine with inadequate knowledge. Primary care professionals cannot be expected to have the specialist knowledge about rare conditions, but when diagnostic overshadowing occurs – meaning that the professional neglects general health needs because of a focus on the primary condition – this is a failure that could easily be remedied by greater awareness. For example, it might be wrongly assumed that people with disabilities are not sexually active, and therefore do not need sexual and reproductive health services. Moreover, if professionals are trained with a narrow focus – attending to a specific problem without seeing the wider social and psychological impacts in a holistic way – then people with disabilities are likely to feel pathologised and their wider needs neglected. This is particularly the case when professionals assume that their patients with disabilities have a poor quality of life, and therefore may not need the same life preserving interventions – such as CPR – as other patients. Evidence shows that people with disabilities, despite their primary conditions, do feel healthy and can be successful in managing their own health needs if they receive the appropriate support and information (Watson 2002, Nazli 2012). Moreover, there is considerable evidence that people with disabilities report a high subjective quality of life, despite their impairments (Albrecht and Devlieger 1999, Amundson 2002).

Negative attitudes on the part of health professionals seem to translate into worse outcomes for consultation with patients with disabilities. Analysis of the 2006 US Medical Expenditure Panel Survey revealed that people with disabilities were more likely than nondisabled people to think that their doctor had not listened to them, treated them with respect, taken enough time, involved them in treatment decisions and explained treatments properly (Smith 2009). Overall, people with disability in this study were between 36% and 78% more likely than nondisabled people to perceive inadequate doctor-patient communication. In the UK, the Formal Investigation into Inequalities in Health initiated by the (former) Disability Rights Commission found that people with mental illness and people with intellectual impairments received a worse service from health professionals, which may have contributed to the poorer mortality and morbidity outcomes they experienced (Disability Rights Commission 2006).

Given evidence of discomfort, negative attitudes and lack of knowledge on the part of health professionals, there is a need to ensure better training and education about disability ( Shakespeare et al 2009, Iezzoni and Long-Bellil 2012). This need has been highlighted by health professionals themselves (e.g. Baker 2012, Wilkinson et al 2012) and has been conceptualized as part of cultural competence (Eddey and Robey 2005). Undergraduate education on disability is often absent or inadequate (Larson McNeal et al 2000);for example, a US survey of graduating dental students found that only 6.2% reported being well prepared to treat patients with disabilities (Chmar et al 2007).

**What do health professionals need to know?**

 Student health professionals need specific clinical education, such as for nurses working with people with complex neurological problems (Baker 2012) , or for medical students who need to have good teaching about physical and rehabilitation medicine (Gibson et al 2010, Gutenbrunner et al 2010). However, ensuring a technical grasp of clinical issues is not sufficient to meet the objections of disabled people and their advocates, or to improve their health outcomes. Indeed, an over-medicalised and pathologised approach has been widely criticized by disability advocates (e.g. Oliver 1990). Disability should be understood holistically, and as a human rights as well as a health issue.

Health professionals need to understand how disability affects a person and their family in every aspect of their life, and specifically to have an appreciation of the human rights dimension of disability. Ensuring this is a legal obligation for governments of countries which have ratified the Convention on the Rights of Persons with Disabilities (UN 2006). Article 25 (d) states that States Parties shall:

“Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care.”

Bearing this legal standard in mind, and adapting Kirschner and Curry (2009), the following competencies could be proposed:

1. Framing disability within the context of human diversity across the lifespan and within social and cultural environments.

2. Skills training for asessment of disability and functional consequences of health conditions, considering implications for treatment and management.

3. Training in general principles concerning etiquette for interactions with persons with disabilities.

4. Learning about roles of other health care professionals forming integrated teams to care for persons with disabilities.

5 Understanding the legal framework of national anti-discrimination legislation, the Convention on the Rights of Persons with Disabilities, relevant ethical standards, and the principles of reasonable accommodation and universal design.

6. Competency in patient-centered care approaches, including patients’ perception of quality of life.

**Solving the problem**

**Didactic teaching** on disability is very common. In the field of dental hygiene, a study found that 98% of US programs surveyed said they presented material about people with special needs in lectures. However, only 42% of programs required students to gain clinical experience of these patients (Dehaitem et al 2008). While any training is good, having a few hours teaching about disability is likely to be insufficient to change attitudes, instill required knowledge or develop skills (Delucia and Davis 2009, Richard et al 2005).

It could be hypothesized that hearing from those with direct experience of disability might make more impact and be more memorable. For example, Monash University medical students engaged with tutors with intellectual disabilities on a three hour communication workshop, which increased their understanding and comfort levels with this traditionally underserved community (Tracy and Iacono 2008). At Leeds University, a series of seminars for medical students on “valuing diversity” were taught, inter alia, by deaf people, disabled people from the local Centre for Integrated Living, people with mental health conditions and people with intellectual disabilities (Thistlethwaite and Ewart 2003).

Research with dental students shows that prior experience with people with intellectual disabilities is associated with comfort levels in treating this population (DeLucia and Davis 2009). **Supervised contact** with real patients or people with disabilities has been found to have more impact on knowledge and attitudes than lectures alone, for example in improving confidence in working with people with intellectual disabilities (Adler et al 2005). Home visits are typical, and various approaches have been successfully trialed, including inter-professional learning (Street et al 2007, Anderson et al 2010). A successful Glasgow project sent first year medical students to do life history interviews with people with chronic illness and their carers in their own homes (Mullen et al 2010). In Florida, paediatric residents visited families with disabled children and heard their stories (Sharma et al 2006). Innovative senior mentoring programmes in South Carolina involved students being paired with an older person and doing a series of assignments, ranging from clinical assessments to health promotion to home safety assessments (Corwin et al 2008).

**Virtual engagement** has also been attempted. St Bartholemew School of Nursing and Midwifery (London, UK) experimented with an online discussion forum which involved mental health service users educating mental health nursing students in the context of Enquiry-Based Learning (Simpson et al 2008). Twelve service users, recruited from local mental health day centres, were supported to engage with students online and paid a small weekly honorarium. Over six weeks, nearly 3/5 of the students participated, reading or posting messages, averaging seven messages each; by contrast, service users sent an average of nearly fifteen messages each. Two thirds of the students’ subsequent EBL presentations were influenced by these interactions and students valued hearing about first hand experiences of mental illness, while service users valued being taken seriously and having the opportunity to influence future workers. All students and service users interviewed were overwhelmingly positive about the experience.

**Service learning** is an experiential learning approach where students learn by doing, and can offer benefits in disability education for professionals (Gitlow and Flecky 2005). Prior training can enhance the benefits of placement in community facilities, for example with older adults with dementia (Fruhauf et al 2004), and thus improve learning of interaction and communication skills. An Australian study where medical students spent 8 weeks on placement in rural special schools was welcomed by staff and students alike, and reportedly led to better understanding of children with special needs (Jones and Donald 2007). In Leicester, medical students and social workers had 4 week placements in community hospitals, together with training delivered by a Centre for Integrated Living (Anderson et al 2010).

A traditional way of changing attitudes is via **simulation exercises** – for example, spending time in a wheelchair or wearing spectacles that simulate sight loss (Amosun et al 2005, Crotty et al 2000). For example, in one course, students were randomly assigned to spend half a day in a role play of being paraplegic, being blind, being deaf, and being unable to speak, with designated tasks – shopping in a supermarket, visiting an art gallery. IThe aims of such simulations include developing interpersonal skills, increasing empathy and learning about practical issues, such as accessibility (Crotty el 2000), and these experiences seem to be highly valued by participants. While these exercises may give some insight into practical difficulties – including environmental barriers – and negative attitudes, there is a danger of seeing disability in very individualistic terms. If the main problems of disabled people result from poverty, prejudice and discrimination, then sitting in a wheelchair for a half-day is unlikely to result in a full understanding, and may even distort perceptions.

**Clinical contact** is another option. It is important to introduce students to caring for patients with disabilities early in their career, and ensuring that disability is integrated throughout the curriculum and at every stage. Markström et al (2009) found that five week clinical placements for students in healthcare professions reduced stigma associated with mental illness, perhaps through contact with affected persons. Swiss dental students who were able to treat older persons in mobile clinics reported feeling less pity and more frustration than German students, who could observe problems but not help (Nitschke et al 2009).

**Interprofessional education** is particularly appropriate for learning about disability, given that disabled people often engage with a multiplicity of different professionals (Anderson et al 2010). Several studies found that bringing together social work students with medical students, or nursing students with medical students, or a range of health professional students, could be effective (Street et al 2007, Markström et al 2009, Anderson et al 2010, Anderson et al 2011). These interventions can support the real-world partnership environment with which professionals will subsequently be engaged.

**Impact** of these interventions was generally assessed by pre- and post-intervention attitudinal change, tests of knowledge, and/or by student feedback. Across the included studies, significant improvement in knowledge was common, although this sometimes tailed off over time. However, it was sometimes harder to detect improvements in attitudes when the only intervention was one or more lectures. Student evaluations were found to be consistently positive in these studies (e.g. Crotty et al 2000 found 96% positive feedback).

If students are to take disability seriously, it needs to be part of their **assessment**. For example, the Leeds University seminars on valuing diversity were assessed by part of a written exercise that contributed to student grades for the Personal and Professional Development core unit (Thistlethwaite and Ewart 2003). In several cases, Standardized Patient Clinical Cases (Saketkoo et al 2004) or objective standardized clinical encounters (OSCEs) (Crotty et al 2000, Sabharwal et al 2000, Symonds et al 2009) were used to assess student learning, with disabled people being trained as standardized patients.

**Conclusion**

In this talk, I am reporting on a review which included nearly 50 papers describing more than 90 different teaching and learning activities focused on improving understanding of disability and attitudes to people with disabilities. Many of the initiatives display great imagination and have demonstrated effectiveness. It is impossible to say definitively what works best to improve health professional knowledge and attitudes in the area of disability, and different contexts may demand different approaches. However, more such initiatives are needed, particularly in those parts of the world which are unrepresented in this review. Learning from success, and widespread adoption of good practices is required, if the ambitions of the Convention on the Rights of Persons with Disabilities are to be achieved.