



## Equal Rights Irrespective of Disability

A few days ago, on a hot and humid late August morning, I was sitting in the breakfast hall of a cheap hotel in Sarajevo, sipping my third cup of instant coffee – the only type available in a place like this. I was trying to wake up for the challenging day ahead but my mind was still a cloud. The breakfast hall was empty, apart from the family at the table across from me – two boys of primary school age with their backs to me, and the parents facing in my direction. The excited voices of the boys mixed with the clutter of cutlery.

And something was wrong. Something had been wrong for some time, something that wouldn't come into focus. Then suddenly I saw it – the man's face, right in front of me, that I had been looking at for some time without seeing. The face was big, puffy, and dead. In the middle of all the noise and fuss at the table around him, the man sat perfectly still. There was no expression on his face. A child's body shifted in my line of vision to reveal part of the man's large body: one arm was missing below the elbow, with the elbow itself resting on the edge of the table. I leaned to the opposite side to check out the other hand but it wasn't there either. The second elbow, too, was resting on the edge of the table, forming the end of that limb. Then the woman put a huge piece of cake in the man's mouth and he chewed automatically. His vacant eyes, his motionless body gave the impression of an inanimate object, despite the moving jaws. He might as well be a piece of wood forgotten on the shelf of a carpen-

ter's shop one thousand years ago. Then the mother and the children went somewhere and he remained alone, waiting for them to come back, drowned in a deep stupor, either incapable of or unwilling to make the slightest movement on his own.

He looked around 40. Was he a war veteran? If that was the case, he had lived without hands for at least 17 years and fathered the children while handicapped, before he was overwhelmed by depression. Or had he lost his hands more recently, when the children were already born? And was this much worse, I wondered, recalling that Bosnian laws and policies officially privilege disabled persons who are war veterans over other disabled persons? But whatever had torn off his hands, what kind of support system had numbed him so cruelly, I wondered. What kind of health and social care arrangements had let him down so profoundly that he had become the very image of lifelessness?

Fully awake now, I thought about a different world that was lost to this Bosnian man. That other world was now preparing to celebrate the amazing abilities of the disabled, and with this – the spirit of dignity, independence and humanity in the Paralympic Games that would be opening in London in a couple of days. I thought about Theresia Degener, the fabulous member of the UN Committee on the Rights of Persons with Disabilities, a German professor without hands who has a full life and does every-

thing independently – eating, typing and carrying her luggage to a conference. Dear reader, if you do not know what I am talking about, please google her immediately and see one or two of these short videos, because few things can fill you with such immense joy and pride of being born human.

Disability is a natural part of the human experience, but two people having the same disability can live in different worlds. There is – there has always been – the dehumanising world of stigmatisation, care and dependency in which a person with a disability, even if surrounded by loved ones, is a lesser person. And there is – there should always be – the empowering world of independent living in which a disabled person is more accurately described as differently-abled, and participates equally in all areas of life, regardless of their disability. The UN Convention on the Rights of Persons with Disabilities represents the current global consensus that humanity must make a transition from the first world to the second. In this second world, persons with disabilities are equal in their dignity and their rights, and participate on an equal basis with others in all areas of economic, social, political, cultural and civil life.

This issue of *The Equal Rights Review* is focused on some of the key aspects of disability equality to which the UN Convention aspires. Three articles are devoted to the right to independent living, which is central to realising equality for disabled persons. Gerard Quinn and Suzanne Doyle analyse the obligations of the European Union in respect to disability rights at this critical stage, and state clearly what must be done to move from the medical model towards the much lauded “paradigm shift” on disability, particularly through the proper regulation of the EU’s structural funds. Camilla Parker

and Luke Clements argue that institutionalising persons with disabilities is a form of discrimination that deepens their disadvantage, and that there should be no excuse in allowing European Union funds or indeed any public funds to be used to perpetuate this form of discrimination. Georgette Mulhair brings in the research and experience of Lumos, the organisation she directs, and puts together the elements of an indictment of the whole practice of institutionalisation of children with disabilities. She shows how the linkages of disability, ethnicity and poverty have been weaving the patterns of disadvantage for children in Europe. The testimony provided by Joshua Hepple, a young British man living with cerebral palsy, provides a glimpse into the reality of growing up with disability in the UK, and the struggle for an independent life.

One of the most difficult outstanding issues in achieving equality for persons with disabilities is the issue of mental capacity. When it comes to autonomous decision-making and freedom to choose how to lead one’s life, the right to equality can easily be in ruins if the person has no legal capacity. Persons with mental health problems and intellectual disabilities are most at risk. Several pieces in this issue highlight the emerging trend from substituted legal capacity exercised through various forms of guardianship to supported legal capacity where the equality and autonomy of the person are the starting point. To be sure, this is not the realm of light choices. I personally am grateful not to be in the place of the judge in the recent UK case of E. summed up in the Special of this issue. This judge had to decide whether it would be legal to continue to force-feed E, a 32-year-old anorexic woman, overriding her stated will, on the basis that suffering from the mental illness of anorexia nervosa had deprived her of the ability to make decisions in her own best interest.

There are some excruciatingly difficult questions surrounding mental capacity. For example, is there a state of mind in which one can make a decision to die and which cannot be contested as being due to mental illness? The principles on which such issues should be approached are outlined in human rights law, but their operationalisation in national laws and policies is another matter.

In recognition that their mental capacity legislation is not yet in compliance with the requirements of the UN Convention on the Rights of Persons with Disabilities, and taking the challenge of introducing such legislation seriously, some states, including Finland, Ireland, the Netherlands and Norway, are yet to ratify the Convention. Many other states that have ratified the Convention, however, are far from meeting this challenge. Lawrence Mute analyses mental capacity law in Kenya and shows why it falls short of the standards enshrined in the Convention.

To build a world in which disabled persons would enjoy equal rights fully, technology

is an essential tool. The interview with Hiroshi Kawamura allows a quick look at cutting edge developments in this area, where companies such as the one of which he is CEO, are developing disability-friendly new information and communication technologies, as well as new instruments and tools to help overcome a disability. The Paralympic Games currently taking place are a triumph of technology as well as humanity. It is stunning to watch, for example, the athletes running on artificial legs. But as Kapka Panayotova of the Bulgarian Centre for Independent Living suggests, in the end culture is more important than technology. In order for the fascinating technologies that compete with science fiction to be an emancipating and empowering force, we need the attitudes that are inspired by certain humanistic values. Human rights are at the heart of such a culture of humanism. Without them, we would be helplessly looking at people who might as well be an embodiment of lifelessness, like pieces of wood forgotten on the shelves of the universe one thousand years ago.

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