

Understanding disability

An interview to

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Editor: As you have written in your book «Disability rights and wrongs, which has been published in its Italian edition (Erickson, 2017), your studies highlight the need for an approach that can enable us to observe and manage social relationships – not only people with disabilities and their choices. However, changing this perspective, though necessary, is not easy...

Tom Shakespeare: I agree. There is a stubborn set of prejudices about disabled people. Non-disabled people fear disability, they consider that disabled people are incompetent and cannot speak for themselves. Even when motivated by kindness, they are inclined to over-protect disabled people.

E: You suggest «a critical realist approach», a perspective based on the awareness that «people are disabled by society and by their bodies and minds». This means conveying the social experience of disability, avoiding both oversimplifications and preconceptions. Would you consider a general agreement with this view possible, in the hope of a real change happening?

TS: I think my approach is common sense. Disabled people have issues of their health, maybe their mental health, but also face barriers in the environment, barriers of prejudice and discrimination. Therefore, the responses have to be medical, psychological, architectural, social work, education provision, employment law... disability is a complex problem which demands a multi-faceted solution. I think most people can understand this.

E: Birth and end of life, care, social and sexual relationships of people with disabilities – for years all these matters were avoided and considered «taboo». Currently attempts are being made to tackle them pragmatically. In your opinion, what are the most urgent issues that need to be attended to?

TS: I think we have to explore how to provide care, without paternalism. I think we have to find ways of respecting the very human need for love and intimacy. And I think we need to think about how to provide informed choice for prospective parents in their pregnancies.

E: In your opinion, how far have we come towards a real inclusion of people with disabilities? However, there are still significant differences between countries and continents – what can be done about it?

TS: I think we have made good progress, partly thanks to the *Convention on the Rights of Persons with Disabilities*. But there is still much to do. I think it is interesting that different countries have strengths in different areas. For example, I am very interested in Italian policies and practices over the last few decades: mental health reform, inclusive schooling, the role of cooperatives. We can certainly all learn from each other. None of us has got it right, yet.

E: According to your experience, how important is it to maintain an ongoing dialogue among professionals who deal with disability, to share positive experiences?

TS: I feel we have to have partnership – between disabled people and parents of disabled children; with professionals in health and education and social care; with policy-makers. We need to recognise and respect the different expertise that everyone brings to this partnership. Honest dialogue and respect is the key to the partnership.

E: In your opinion, what are the pillars of inclusion?

TS: Inclusion depends on: commitment to equality; recognition of difference; respect for dignity.

E: And finally, what are the threats that could hamper the further progress of inclusion and could make the lives of people with disabilities worse?

TS: I think the policies of austerity which dominate in global politics are deeply problematic for disability inclusion, which is often based on social spending. I think populism and suspicion of governments and professionals can undermine trust and also challenge the legitimacy of social transfers towards disabled adults and children.

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