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Article:

Do disabled people need a stronger social model: a social model of human rights?

[AQ1]

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ABSTRACT

We introduce the social model of disability by reflecting on its origins and legacy, with particular reference to the workof the Union of the Physically Impaired against Segregation. We argue that there has been a gradual rolling back of the rights and entitlements associated with the social model of disability. Yet no alternative for the social model has been proposed in response to such threats to disabled people's human rights. Disabled people need a stronger social model that acts as a means to a society which enables and ensures their rights; the right to live a dignified life, as well as to live in an environment that enables people to flourish with disability.[AQ3]

Keywords: Disability   ; social model   ; human rights   ; social model of human rights

A social model legacy

The global disability community and movement sadly recently lost a giant in Mike Oliver. He is often seen as the father of the social model of disability (Oliver 1983), an expression he first coined. Nonetheless, the social foundations of the model are contained in the ground-breaking insights of the Union of the Physically Impaired against Segregation (UPIAS) which originated in 1972 in the United Kingdom. The UPIAS was created by disabled people like Paul Hunt, Vic Finkelstein, and Ken and Maggie Davis. They all had local and global experiences of segregation. For example, Hunt (1966) drew on his experiences of being stigmatised and institutionalised in theUnited Kingdom; and Finkelstein (2001) on his experiences in the anti-apartheid movement in South Africa, where he realised his imprisonment was more accessible to him than general society. The UPIAS argue that:

> … it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. (1976, 4)

It is worth noting that the UPIAS (1976) did not disregard impairment and understood that a person could have (mild) impairment with no experiences of disablement and exclusion from society.

Similarly, the UPIAS (1976) noted the need for medical treatment of impairment but protested against medical understandings (or medical models) being the sole way in which disability is understood. In this way, they also argued against medical and other professional controls or power over disabled people's lives, arguing for independence but also integrated or interdependent living. Maggie and Ken Davis demonstrated this in the way in which they formed a cooperative, as well as planned and built an Independent Living Centre run by disabled people. Their definition of independence was linked to disabled people having control and making autonomous or supported choices, about, for example, when to get up, when to eat or what care they wanted from professionals. It was working and living together interdependently as a family, group or collective with other disabled people that financially and socially enabled people to have control and choices. It never meant disabled people living in isolation, being imprisoned or having to manage everything on their own, in keeping with a neoliberal marketplace economy (see Finkelstein 2007).

The aims of the UPIAS were full participation in society and campaigning focused on the plurality of all those issues, whether they were linked to accessing medical care, transport, employment, education and welfare sectors or ending societal discrimination through rights legislation. The social model had an enormous impact in UK society, by challenging social discrimination and normative assumptions about disability. It was foundational to the Disability Discrimination Act (1995) and the later Equality Act (2010) which replaced it, with the idea of protected characteristics. The social model also influenced the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations 2006), which was one of the most innovative and far-reaching pieces of legislation. Yet while most countries have signed up and ratified the CRPD, it has not always been enforced by national governments or given adequate resources for implementation.

The social model is sometimes viewed in terms of the removal of barriers or changing attitudes or perceptions. It is, however, more radical and influential than that. Finkelstein (2007) argued that models had to fit their times and needed to change with those times. The social model has, however, become fixed into a narrow rights-based approach, which saw the acquisition of rights as an end in itself. He foreshadowed this:

The ideological problem facing the disability movement in the UK from the 1990s onwards was whether the social model of disability was still relevant in guiding our struggle or whether social changes had advanced so far that the original model no longer reflected the social context in which it had been created? Is the 'rights', or 'potpourri', model of disability now more in tune with the market economy expanding into the health and social services sector of society? (Finkelstein 2007, 14)

Oliver (2013), too, was not precious about the social model and open to its critiques but felt that all of 'the talking' was distracting from the way in which austerity and the broader neoliberal project were eroding the collective rights that the disability movement had built up in the United Kingdom. The general consensus was that the disability movement and charities were failing to uphold the rights and entitlements that had been so hard won, with a new politics of disablement emerging where legislation was being used to police disabled people (Oliver and Barnes 2012).

A social model of human rights?

Much research has been done about the global impact of austerity on the creation of more disability since the economic crisis of 2007–2008. Significant evidence has been published that the rolling back of the welfare state in developing countries is also affecting disabled people negatively, and some argue that this has been leading to more impairment and increased risk of early mortality. [AQ4] This point does not have to be made again, and disabled people have been at the forefront of global activism and protests against cuts, marketisation and privatisation of services and the global erosion of their human rights (Berghs et al. 2019). What they have not been given by disabled people is an alternative to the social model. As some have asked, is the social model fit for purpose or do we need a more active model to set out an agenda for change (Levitt 2017)?

When our team did research on public health and disability with people who were politically and socially active in the United Kingdom, they noted that the social model was being eroded but that legislation was still important (Berghs et al. 2016). It was legislation like the Human Rights Act (1988) that offered people legal protection and a way in which they could fight to uphold their rights and survive. In many ways, they felt as if the Equality Act (2010) was acting as a token instrument. Yet, instead of a human rights approach, they argued for a social model of human rights (Berghs et al. 2017). Our team was excited by this and we thought that the grassroots disability movement and

individual activists would later begin elucidating what this would consist of. Post Brexit, with the United Kingdom leaving the European Union, there have also been calls to replace the Human Rights Act (1988) with a British Human Rights Act, further acting as an impetus to think how the social model could become legislation and create an environment inclusive to disability rather than despite of disability. We have seen from the CRPD (United Nations 2006) and from what is happening globally in times of austerity that as the economic situation changes, disabled people's human rights are being affected and that any new Human Rights Act needs to have a clause to ensure that the rights of disabled people, as a protected group, cannot be rescinded but should be enforced. Disabled people are currently being forced to defend their basic 'needs', but we argue instead that they have rights to flourish with disability and that it is society that should enable these rights. This is what a social model of human rights act could set out in legislative form.

What politically and socially active disabled people are arguing for was what Finkelstein (2007) was elucidating; they want a social model of human rights that is a means to an end and not the end in itself. It should be a means to change society (and its collective values), in addition to upholding the human dignity of disabled people's lives in every aspect of society. Too often this has been interpreted in terms of singling out disabled people and creating specific legislative instruments or having to make accommodations or adjustments for them – this almost identifies disability as a problem, instead of changing society to become more inclusive of that diversity as a norm (Williams et al. 2018). We would argue that the current approach of focusing on the removal of barriers, attitudinal change and what adjustments are 'needed' does not encompass social, medical or even charity models of disability. Instead, it creates the boundaries of what a lack of citizenship, and by extension rights, implies, in terms of a life that lacks true citizenship and rights in society. This is why, we assume, disabled people argued for a social model of human rights, because they felt that their human rights were being denied and eroded by society. It also points to what they wanted the social model to enable, because it is currently missing in the United Kingdom – rights to be human. This is very basic, the right to live and have a dignified life as a human being. Disabled people felt that they were not being treated as human by society and, because of the impact of austerity, thought some people's lives were not dignified as human. We would argue that society should and can do better, in terms of responsibilities of a social contract to all their citizens, to enable not just living in dignity but being able to flourish with disability. Furthermore, this is a matter of justice, equality and rights, which should be established as equitable norms rather than an aspiration associated with equality of opportunity.

Finkelstein (2007) argued that models are used as tools and only make sense in particular times. While we still do not think that academics should be the ones outlining what a social model of human rights could look like and what it is now inclusive of, we think that disabled people now urgently need a new stronger social tool for justice, rights and entitlements in society. It seems as if instead of focusing on differences and disagreements, the time has come to think of what unifies; for example, regardless of identity politics and what identities people feel they ascribe to, everyone is in agreement that the political and economic time has come to say enough is enough and uphold the legacy that disabled people have been given by reinterpreting what the 'social' now means. For example, thinking through how it links to different types of 'rights' in terms of, for example, welcoming a greater diversity and intersectionality of identities across the life-course, acknowledging experiences of pain, understanding differing needs for interdependence or debating what 'rights' could be inclusive or exclusive of, and how to sensitively define them in local and global terms. We hope that we have engaged with the spirit in which disabled people shared these insights with us, and that we are doing justice to those deliberations and debates (Berghs et al. 2016, 2017) by asking for a new model, a tool that can act as a hammer (Oliver 2004).

Disclosure statement

No potential conflict of interest was reported by the authors. The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the PHR, NIHR, NHS or the Department of Health.[AQ5]

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