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Chapter 7 Disability equality

The last civil right?

Richard Rieser

People and society now and in the past have great difficulties understanding disability as an equality issue. Old stereotypes are continually recycled in the media, drawing on a history of disabled people’s oppression. The paradigm shift, from viewing us individually or as a medical problem, to people with human rights oppressed by socially constructed barriers, is still obstructed by ‘disabilism’ which continues to ‘other’ those with long term physical or mental impairments. Despite legislation and international human rights’ treaties, disabled people continue to lag behind their fellow humans globally on nearly every indicator. In this chapter the author expertly unpacks these contradictions over time and space and signposts a route to understand and implement equality for disabled people.

In this chapter I will examine different ways that the dimensions of disability and the struggle for disability occur. This will lead on to a discussion of traditional, medical and social models of disability, their roots and impact. Recently regressive formulations such as the biopsychosocial model have been adopted to push through austerity measures. Others have argued that the United Nations Convention on the Rights of Persons with Disabilities now gives a more enforceable human rights model. This is examined through a discussion of the enduring oppression that is disablism and the continuing threat of NGOs not run and controlled by disabled people and ways to coproduce with them. I go on to examine the global and UK statistics of disability over the last 40 years. This leads on to the disablist actions of the UK Government during Austerity. Providing a short historical account of the treatment and thinking about disabled people then helps us to understand the origin and recycling of stereotypes of disability and how to challenge these in literature and the media. This approach is illustrated through the UK Disability History Month. Lastly, I analyse the impact of the global Covid-19 pandemic on disabled people to illustrate the continuing lack of our human rights and why we still need a grassroots disabled led movement, based on the thinking of the social model of disability, to challenge and bring about disability equality.

# Dimensions of disability and the struggle for disability equality

At least 15 per cent of the world’s people have a significant, long-term, physical or mental impairment that can and usually does disable them from taking part in the usual educational, social and economic activities in their community (WHO, 2011). This is due to barriers in attitudes, in the built environment and in the way society is organized, which prevent us from participating on an equal level with others. The reason why most of these barriers exist is because societies have until very recently not recognized that the systematic way in which they discriminate against disabled people, when backed by discriminatory laws and practices of the state, often amounts to oppression. Barnes (1991)gives a full account of the discrimination which disabled people encounter in all areas of life.

This oppression has developed from our history, from myths and beliefs that attribute characteristics to disabled people that are unrelated to the reality of disabled people’s lives. Such collections of attitudes often determine how non-disabled people respond to the ‘different’ in their midst; how they form stereotypes of the disabled person as saint, sinner, super-hero, freak, victim, obsessive avenger, isolationist, the butt of jokes, just a burden or someone to be pitied. The particular form of stereotyped thinking depends on a given society’s history, its explanation of how it has come to be and the resultant culture.

In December 2006 the United Nations adopted a ground-breaking new human rights treaty recognizing our oppression and requiring all states’ parties who adopt and ratify this treaty to ‘undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability’. Thus Article 1 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) addresses the need for equality for disabled people throughout the world.[[1]](#footnote-1)To convince the United Nations of the need for the Convention, it was necessary to demonstrate how disabled people were systematically denied the human rights which others take for granted. In the United Kingdom, which ratified the Convention in June 2009, we have also passed into law the 2010 Single Equalities Act, which addresses disability and the other equalities issues addressed in this book. These two statutes can provide a new impetus for developing disability equality and for promoting inclusion.

The dimensions of inequality to do with gender, sexuality, ’race’ and class all interact with disablement to create additional oppressions for those subjected to one or more of these oppressions. However, until very recently, the arguments for disability equality have often been ignored in the development of thinking about equal opportunities. In 2005 the Cabinet Office produced a far-reaching strategy to achieve disability equality for disabled people in the UK. Tony Blair, then prime minister, writing the Foreword, had this to say:

This report therefore sets out an ambitious vision for improving the life chances of disabled people so that by 2025 disabled people have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society.

(Cabinet Office, 2005, p. 6)

This commitment has not survived the austerity measures of the post-2010 Coalition government, followed by the Conservative governments from 2015, and is even less likely in the post-Brexit environment. In October 2016 the UNCRPD Committee, following a complaint and an in-depth investigation, concluded that UK welfare reforms have led to ‘grave and systematic violations’ of disabled people’s rights.[[2]](#footnote-2)

In the wake of all this and seeking to add disability rights to the levelling up agenda, Boris Johnson in his Foreword to a new Disability Strategy in August 2021, muses upon there being a single vast city with 14 million:

where residents were much less likely than those elsewhere to have a job or even any qualifications at all. Where children were twice as likely to become victims of crime, far fewer adults owned their own home and the impact of Coronavirus had been distressingly disproportionate…. Yet these statistics relate to the daily reality of 14.1 million living with a disability.

(Forward to National Disability Strategy, 2021)[[3]](#footnote-3)

The strategy itself does not include the views of disabled people’s own organisations, is depressingly sparse on details and new money or the promise of comprehensive legislation that is needed, and while saying it is based on a social model approach confuses impairment and disability. The Report has been widely criticised by Disabled People’s Organisations.[[4]](#footnote-4)

In this chapter, I begin by looking at how disablement is defined and modelled. I then look at the extent of disability, worldwide and in the UK, and the impact and scope of the UNCRPD and the Equalities Act for developing disability equality. Next, I give a brief history of disablement, including the growth of the Disabled People’s Movement and our struggle for civil rights. I conclude with an examination of the way in which ideas of disability equality can be raised in the general school curriculum. This can help counter prejudicial and discriminatory attitudes which lead to harassment and bullying. In English schools, 80 per cent of disabled pupils report bullying: two-and-a-half times the level of non-disabled children (DCSF, 2008; EHRC, 2010a). Outside school, hate crimes against disabled people have only recently been recognized as a largely hidden but serious human rights abuse. The United Kingdom Disabled People’s Council report identified media reports of 69 murders and 549 serious attacks on disabled people in the UK in the three-and-a-half years to July 2010 (SCOPE, 2008; UKDPC, 2010). The Equality and Human Rights Commission (EHRC) Report *Hidden in Plain Sight* (2011) found systematic and under-reported harassment:

The inquiry has confirmed that the cases of disability-related harassment which come to court and receive media attention are only the tip of the iceberg. Our evidence indicates that, for many disabled people, harassment is a commonplace experience. Many come to accept it as inevitable.

A more recent Report from the EHRC *Being disabled in Britain: A journey less equal* (2017, p. 33) says:

Academic research published in 2016 found an association between SEND and being a victim of bullying in schools, suggesting that wider social inequalities are reproduced in schools. On the basis of surveys carried out by the anti-bullying charity Ditch the Label (2015) the likelihood of being bullied can vary greatly by disability: 40% of children and young people with no disability reported being bullied. This compares with: 58% with a physical disability; 62% with a learning disability; 67% with autism/Asperger syndrome.

Though there is some evidence of reductions in bullying rates at school, disabled students remain disproportionately affected.

Much still needs to be done. Article 8 of the UNCRPD requires governments as part of awareness-raising to ensure ‘Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities’.

# Three ways of viewing disablement: the ‘traditional model’, the ‘medical model’ and the ‘social model’

## The ‘traditional model’ of disability

The ‘traditional model’ is a many-headed monstrosity that has helped human beings in all societies and cultures give an explanation to that which they did not understand. It relies on belief in the supernatural, religion, magic and fantasy. It is an ‘othering’ process that helps deal with fear, curiosity and pain caused by the occurrence of physical and mental impairment and our mortality. Impairment is ever present and is seen as a threat to a sense of well-being by non-disabled people (Rieser, 2008a). Here are just a few such notions:

• Disabled people bring good luck or have supernatural powers, sixth sense or ability to tell the future.

• Disabled people are a punishment from God or bad karma.

• Disabled people are bad luck or evil.

• Disabled people are figures of fun, the butt of jokes or jesters/clowns that help us forget our troubles.

• Disabled people are possessed by demons.

• Disabled people are vengeful and have a chip on their shoulder. Disabled people are a burden on everyone else.

• Disabled people are asexual and/or perpetual children.

• Disabled people are contagious and have to be kept separate from everyone else,

While we may think such ideas are long gone, a surprising number of people in many cultures are influenced by them and they persist in the stereotypes promulgated in literature and the media (Rieser, 2004). Many of these ideas arise from the way we have been perceived and treated in the past, as will be seen from the section of this chapter ‘The history of disablement’. The daily language that arises from such notions and misunderstandings is commonplace. A survey by the Anti-Bullying Alliance (2014)suggests:

that adults are perpetuating and normalising bullying behaviour by using discriminatory language in their everyday conversations, with some directing abusive words at disabled people or those with special educational needs (SEN). The findings […] show that four in ten (44%) adults use the words ‘spaz’, ‘spastic’, ‘retard’ or ‘mong’ in casual conversation; half of whom justify doing so as part of ‘banter’. In addition, 65% hear others using these words in conversation, with over a third (37%) witnessing them being used online. When it came to using the words directly towards another person; almost a third (30%) admitted to doing so; with 1 in 5 saying they had done so just as ‘banter’ and 1 in 10 to be deliberately insulting.

## The ‘medical model’ of disability

The ‘medical model’ sees the disabled person as the problem. We are to be adapted to fit into the world as it is. If this is not possible, then we are shut away in some specialized institution or isolated at home, where only our most basic needs are met. The emphasis is on dependence, backed up by the stereotypes of disability that call forth pity, fear and patronizing attitudes. Rather than on the needs of the person, the focus is usually on the impairment. With the medical and associated professions’ discourse of cures, normalization and science, the power to change us lies with them. Often our lives are handed over to them. At the time of writing, the continuing benefits cuts culture has reinforced these notions and impacted on disabled people through the disproportionate impact of Covid-19 and disproportionate fatalities as recorded by the UK Office of National Statistics:

The pandemic has shone a light on pre-existing inequalities in the UK. If we are to build back fairer, we need the fullest possible understanding of the inequalities that have been highlighted and/or reinforced as a result of COVID-19. In November 2020 when the ONS published their finding that disabled people accounted for 59% of COVID-19 deaths, it became clear that inequalities on the grounds of disability were a critical area to understand.[[5]](#footnote-5)

Other people’s (usually non-disabled professionals’) assessments of us are used to determine where we go to school; what support we get; what type of education; where we live; whether or not we can work and what type of work we can do; and indeed whether we are even born at all, or are allowed to procreate. Similar control is exercised over us by the design of the built and information environment, presenting us with many barriers, thereby making it difficult or impossible for our needs to be met and curtailing our life chances. Whether it is in work, school, leisure and entertainment facilities, transport, training and higher education, housing or in personal, family and social life, practices and attitudes disable us.

Powerful and pervasive views of us are reinforced in language, and in the media, books, films, comics and art. Many disabled people internalize negative views of ourselves that create feelings of low self-esteem and achievement, further reinforcing non-disabled people’s assessment of our worth. The ‘medical model’ view of us creates a cycle of dependency and exclusion that is difficult to break.

‘Medical model’ thinking about us predominates in schools where special educational needs are thought of as emanating from the individual who is seen as different, faulty, and needing to be assessed and made as normal as possible (see Figure 7.1).

Figure 7.1 The medical model.

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## The ‘social model’ of disability

If, instead of focusing on differentness within the individual, the focus were on, for example, all children’s right to belong and to be valued in their local school, then we would be asking ‘what is wrong’ with the school and looking at the strengths of the child. This second approach is based on the ‘social model’ of disability. This model views the barriers that prevent disabled people from participating in any situation as being what disables them. The social model makes a fundamental distinction between impairment and disability. *Impairment* is defined as ‘the loss or limitation of physical, mental or sensory function on a long-term, or permanent basis’, whereas *disability* is ‘the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers’ (Disabled People’s International, 1981, in Dreiger, 1989). Article 1 of the UNCRPD demonstrates how this latter approach is at the heart of a human rights approach to disabled people: ‘Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.’

In recent years this social model approach to disability has been adopted by the World Health Organisation, UNESCO, UNICEF and the World Bank. In the UK it formed the basis of the Public Sector Duty to Promote Disability Equality in the 2005Disability Amendment Act, which was much diluted in the Equality Act (2010) as it was seen as a bureaucratic burden. In the original wording, the Equality Duty was a powerful audit tool to challenge institutional attitudes, practices and barriers. This demonstrates why strong human-rights based legislation is necessary to challenge and eradicate disability discrimination in all areas. The full incorporation into UK Law of the UN Convention on the Rights of Persons with Disabilities, would provide a strong impetus though mechanisms of monitoring, implementation and enforcement would still be needed.

The Disability Movement, which consists of organizations controlled by disabled people, comprises those disabled people and their supporters who understand that they are, regardless of their particular impairment, subjected to a common oppression by the non-disabled world. We are of the view that the position of disabled people and the discrimination against us are socially created. This has little to do with our impairments. A good recent formulation of the importance of the ‘social model’ to disabled people has come from the Umbrella Disabled People’s Organisation (DPO) in the UK Inclusion London.[[6]](#footnote-6)

What is powerful and liberating about the Social Model is that it *does* reflect Disabled people’s real life experience, and puts forward a radical and practical approach to ending Disabled people’s exclusion and oppression that does not require Disabled people to change who they are in order to be deemed to be entitled to the same rights and opportunities as non-disabled people.

(Inclusion London, 2015)

As disabled people, we are often made to feel that it is our own fault that we are different. The difference is that some part, or parts, of our bodies or minds are limited in their functioning. This is an impairment. This does not make us any less human. But most people have not been brought up to accept us as we are. Through fear, ignorance and prejudice, barriers and discriminatory practices develop that disable us. This understanding of the process of disablement allows disabled people to feel good about ourselves and empowers us to fight for our human rights (Oliver, 1990; Morris, 1991; Mason and Rieser, 1994) (see Figure 7.2).[[7]](#footnote-7)

## The ‘biopsychosocial model’ of disability

Perhaps to match the need to cut support to disabled people in times of austerity, a variant on the ‘medical model’ has become popular with insurance companies such as Unum, with doctors being asked to evaluate disabled people for benefits and Government Departments such as the Department of Work and Pension. It effectively says that many of the symptoms of the impairing condition are learned behaviours and can be discounted. This is the ‘biopsychosocial model’.

Figure 7.2 The social model.

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The biopsychosocial model broadly attributes disease outcome to the intricate, variable interaction of biological factors (genetic, biochemical, etc.), psychological factors (mood, personality, behaviour, etc.), and social factors (cultural, familial, socioeconomic, medical, etc.) (Santrock, 2007). While sounding plausible, the model entails an easy regression to viewing the person’s impairment as partly due to their perceptions and so, if there is insufficient medical evidence for their degree of restriction, then such restriction is not worthy of support. The internalized oppression that disabled people acquire from negative attitudes towards impairment clearly need combating, and this should be achieved through understanding the barriers in society, solidarity and mentoring from other disabled people in a similar position, not from medical model-inspired professionals who deny our self-knowledge and experience. As Debbie Jolly, one of the founders of Disabled People Against the Cuts, has written:

One of the main advocates of the bio-psychosocial model, Lord Freud ([at the time] Westminster’s Minister for welfare reform) claims that it is based on evidence. It is not. It is a right wing model led by profit and the market. It incorporates the worst aspects of neo-liberalism. It targets disabled people and ridiculously claims that we can think ourselves out of being disabled.

Its underlying theme repeats the mantra that ‘work will set you free’. But this is not about work, despite the endless rhetoric; this model is an ideological cover for attacking disabled people and reducing every single right to financial support that has been achieved.

(Jolly, 2012)

I will illustrate the medical and social models of disability, with reference to my own history. I had polio in 1949, which led to the loss of muscle in my left leg, right arm and back. By the time I was 6 six years old, my impairment was not major – I could walk, swim, ride a bicycle and so on – but I walked with a limp. However, when I expressed the desire to attend the local primary school, which was all built on one level, the head teacher refused to have me, claiming that I was a fire risk. I was accordingly sent to a school for ‘the physically handicapped’. This was my first experience of disablement. The school smelled like a hospital and I did not want to go there. So my parents kept me off school until the London County Council (LCC) agreed to pay for me to attend a private ‘progressive’ school that was not very good. There I was diagnosed as having ‘learning difficulties’ and ‘behaviour problems’. Seven years later I chose to leave and went to the local secondary modern, a year below my age group. Again I was disabled by not being allowed to use the lift in the six-storey building, by being bullied and being made to feel bad about myself in PE. Despite this, I did get the necessary O and A levels to enter university, though at some considerable cost to my self-esteem.

Later as a teacher I experienced barriers in gaining entry (Medical Fitness to Teach), carrying out my role as a Secondary School Geography and Humanities teacher (not having one room, but many in a three-storey building and at times not being supported by management when some children abused me for my impairment) and eventually being identified for compulsory redeployment in part because of my impairment. I fought with a grievance and this led to me being seconded to advise on disability and the curriculum in the last three years of the Inner London Education Authority. In all of these situations people were disabling me by presenting barriers to my equal participation. These events occurred before the Disability Discrimination Act introduced in 1995, though I experience discrimination to the present day, as enforcement is largely left to the individual.

# The Disabled People’s Movement

The Disabled People’s Movement represents the view that the ‘cure’ to the problem of disability lies in the restructuring of society. Unlike medically based ‘cures’, which focus on the individual and their impairment, this is an achievable goal and to the benefit of everyone. This approach, referred to as the ‘social model’, suggests that disabled people’s individual and collective disadvantage is due to a complex form of institutional discrimination as fundamental to our society as social class exploitation, sexism, racism, heterosexism or homophobia. This leads to discrimination and the internalized oppression we experience. This is not to deny or devalue the discomfort and pain we often experience as a result of having an impairment. Indeed, a number of disabled writers (Morris, 1993; Crow, 1996; Shakespeare, 1992; Oliver, 1996; Shakespeare and Watson, 1997) have argued that the ‘social model’ of impairment must include these experiences – for example, pain, discomfort and dying – and that the Disabled People’s Movement will only attract larger numbers of disabled people if it takes these ideas and practices on board. There has been understandable resistance from those who experienced their lives as dominated by the ‘medical model’, and the real problem is that our current ‘social model’ has not been developed to encompass our experience of impairment and so to develop our own responses to it.

# The human rights approach to disability

Theresia Degener, a disabled activist, lawyer and previous chair of Convention on the Rights of Persons with Disabilities (CRPD) committee and others have argued that the human rights model of disability, based on the CRPD, is superior to and more comprehensive than the social model of disability[[8]](#footnote-8). Degener argues that

while it is true that the social model of disability has been the prevalent reference paradigm during the negotiation process, my understanding of the CRPD is that it goes beyond the social model of disability and codifies the human rights model of disability.

The social model was developed by academics and activists and went in two directions. Firstly, though it made an important contribution to staking out a new area of Disability Studies, it has often been critiqued as inadequate a) not dealing with pain and other impairment related issues, b) not being useful for experiential intersectionality of gender, race, class, sexuality and disability, c) not dealing with eradicating types of impairment, d) was good at identifying barriers but did not relate to universal rights. Secondly, the social model was developed by and used by disabled activists to give solidarity and a common struggle against oppression across different impairments, to empower isolated individuals and make them feel part of a wider struggle and set a direction for action leading to real change for disabled people. This is still as relevant today as ever.

Proponents of a human rights model do have some important points. 1) The social model does not seek to provide moral principles or values as a foundation of disability policy only an explanation of disablement. 2) The social model supports anti-discrimination policy civil rights reforms; the human rights model of disability is more comprehensive in that it encompasses both sets of human rights, civil and political as well as economic, social and cultural rights. 3) Whereas the social model of disability neglects the fact that disabled people might have to deal with pain, deterioration of quality of life and early death due to impairment and dependency, the human rights model of disability acknowledges these life circumstances and demands them to be considered when social justice theories are developed. 4) The social model of disability neglects identity politics as a valuable component of disability policy, whereas the human rights model offers room for minority and cultural identification. 5) The social model of disability is critical of prevention policy; the human rights model offers a basis for assessment when prevention policy can be claimed as human rights protection for disabled persons. 6) Whereas the social model of disability can explain why two-thirds of the one billion disabled persons in this world live in relative poverty, the human rights model offers a roadmap for change.

The social model approach is the most powerful perspective to achieve our human rights. This is because:

i It is empowering to disabled people to understand that barriers disable us. Although we need support and health interventions, the lack of education, employment, independent living, access, family life, parity before the law and in the political system, oppressive cultures, prejudicial attitudes and discrimination is what diminishes our lives.

ii Recognising our solidarity across different impairment groups gives us unity of purpose, while educating us to take each other’s needs into account.

iii It enables us to build our DPOs by empowering an ever growing number of disabled people and their non-disabled allies to force governments to fully implement the disability and other human rights they have signed up to deliver. Both the social model and human rights model start from the perspective that it is barriers in society that disable and not the older idea that the disadvantage resides in the person as a result of their impairment. Only the social model perspective helps us to build a unified Disability Movement.

# Importance of a social model approach

In addition to this, the obsession with finding medically based cures distracts us from looking at causes of either impairment or disablement. In a worldwide sense, most impairments are created by oppressive systems – hunger, lack of clean water, exploitation of labour, lack of safety, child abuse, wars or lack of access to medication and rehabilitation (see below).

Clearly, the ‘social model’ has important implications for our education system, particularly with reference to primary and secondary schools. Prejudicial attitudes towards disabled people and indeed towards all minority groups are not inherited. They are learned through contact with the prejudice and ignorance of others. Therefore, to challenge discrimination against disabled people, we must begin in our schools.

Our fight for the inclusion of all children, however ‘severely’ impaired, in one mainstream education system will not make sense unless the difference between the ‘social’ and the ‘medical’ model of disability is understood. Only a social model perspective in education leads to a dynamic school change process that leads in turn to inclusive education (Table 7.1from Rieser (2008a, p. 28); see chapter 8, this volume, for a discussion of disability and education).

Table 7.1 Types of thinking about disabled people (DP) and forms of education

| Thinking/model | Characteristics | Form of education |
| --- | --- | --- |
| Traditional | DP a shame on family, guilt, ignorance. DP seen as no value. | Excluded from education altogether. |
| Medical 1 | Focus on what DP cannot do. Attempt to normalize or, if cannot make to fit into things as they are, keep them separate. | Segregation, institutions/hospitals, special schools (with ‘expert’ special educators). |
| Medical 2 | Person can be supported by minor adjustment and support, to function normally and minimize their impairment. |  |
|  | Continuum of provision based on severity and type of impairment. a) At same location – in separate class/units. b) Socially in some activities (e.g. meals, assembly or art). c) In the class with support, but teaching and learning remain the same. What you cannot do determines which form of education you receive. | Integration in mainstream. |
| Social model map (Figure 7.1) | Barriers identified – solutions found to minimize them. Barriers of attitude, environment and organization are seen as what disables and are removed to maximize potential of all. DP welcomed. Relations are intentionally built. DP achieve their potential. Person-centred approach. | Inclusive education – schools where all are welcome, and staff, parents and pupils value diversity. Support is provided so that all can be successful academically and socially. This requires reorganizing teaching, learning and assessment. Peer support is encouraged. Focus on what you can do. |

The ‘social model’ has empowered many disabled people and has been important in uniting previously disparate, often impairment-based organizations. The self-representation of disabled people has been important in a situation where organizations ‘for’ disabled people, but run by non-disabled people, have sought to do things in our name, but without finding out what disabled people want. On a global scale, the International Disability Alliance (IDA)[[9]](#footnote-9)represents people with disabilities at the United Nations. The IDA brings together over 1,100 organizations of persons with disabilities and their families from across eight global and six regional networks. The IDA emerged from the disabled persons lobby group, the International Disability Caucus, which was a powerful force in the negotiations that led to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The IDA has had some important successes. The previous Millennium Development Goals did not mention disability or disabled people. The Sustainable Development Goals (SDGs)[[10]](#footnote-10)adopted by world leaders to cover the period 2016 to 2030 refers to disability 11 times, and now disabled people’s representative organizations are increasingly more involved in discussions at all levels in their countries about the implementation of disability rights. There remains a large gap between the mass of disabled people and those who speak for them, and what is needed more than anything else is capacity building, making clear the paradigm shift at the heart of the UNCRPD – the shift from people with disabilities as objects to disabled people as subjects, from an individual/medical model approach to a social/human rights model.

In the UK, as a result of the cuts in the era of austerity, coupled with a belief that disability equality had been achieved, we witnessed the demise of the once powerful UK Disabled Peoples Council and its replacement by grass-roots organizations such as Disabled People Against the Cuts and Reclaiming Our Futures Alliance (ROFA). While this may, on the surface, seem progressive, it has also unfortunately opened up a space for large charities and other organizations which take on the mantle of disabled people’s organizations without being controlled by grass-roots disabled people.

The Disability Discrimination Act (1995) was seen by the Disabled People’s Movement as weak and full of ‘get-out’ clauses, such as a ‘reasonable’ discrimination. In addition, the Act did not create a Commission to enforce it and support disabled complainants, although a Disability Rights Commission was subsequently established in 2000. Transport and Education were largely left out of the Act’s provisions, and the legislation only applied to employers with 20 or more employees – thus exempting 96 per cent of employers. After pressure, this was reduced to 15 or more employees, and from October 2004 extended to all employers as a result of new European legislation. The split in the Rights Now Coalition (a group campaigning for civil rights legislation) between the factions ‘of’ and ‘for’ us was patched up, with the establishment of the Disability Rights Task Force.

The Labour government of 1997 did not honour its manifesto commitment to introduce enforceable civil rights legislation for disabled people, but it did introduce the Special Educational Needs and Disability Act in 2001. This extended the DDA to cover the whole education system. In 2005 transport and other areas were brought under the legislation. In addition, a new duty to promote disability equality was introduced for all public bodies, including schools, to have a Disability Equality Scheme. A weakened form of this duty has made its way into the 2010 Equality Act, with public bodies from April 2011 no longer needing to have a Disability Equality Scheme, but only to set vague equality targets. The Equality Act has consolidated and strengthened the scope of challenging disability discrimination with a new category of indirect discrimination and disability-based discrimination. The Duty to Promote Disability Equality followed the introduction of the Race Relations (Amendment) Act 2000, which followed the inquiry into the death of Stephen Lawrence and introduced a Duty to Promote Race Equality on all public bodies.

From April 2011 all previous duties were consolidated into a duty on public bodies not to discriminate against people in the nine protected characteristics: age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex and sexual orientation. None of these developments would have occurred without pressure from the trade unions, community groups and disabled people’s organizations. In 2015/2016 in the UK, the House of Lords Select Committee on the ‘Equality Act 2010 and Disability’, investigating the Act’s impact upon disabled people, concluded that the government is failing in its duty of care to disabled people. From taxi drivers refusing to take disabled people, to ‘disgraceful’ accessibility at sports grounds, to pubs and clubs failing to provide disabled toilets, the report, entitled ‘The Equality Act 2010: the impact on disabled people’, concluded that practice in all areas must be improved.

In the mainstream in the UK the position of disabled people is not improving. There is still a long way to go which requires a change in political will. The National Disability Strategy (2021) does little to address the fundamental barriers, instead leaving change to voluntary actions, and not incorporating the UNCRPD fully into UK Law or introducing enforcement of the rights contained in the Equality Act, which are both desperately needed. The Scottish National Party made a manifesto commitment to do this in Scotland which if implemented will lead to further divergence between the four UK countries:

We will bring forward world-leading human rights legislation to reduce inequality and advance the rights of everyone and ensure human rights are embedded in every aspect of life in Scotland. As part of this, we will incorporate into Scots Law the UN Convention on the Rights of Persons with Disabilities.[[11]](#footnote-11)

# What is disabilism?

Disabilism can be defined as discriminatory, oppressive, abusive behaviour arising from the belief that disabled people are inferior to others. Disablism refers to prejudice, stereotyping, or institutional discrimination against disabled people. The main problem about disablism (also *mistakenly* (sic) known as abilism or ableism) is that it is not easy to identify. In many cases, people do not realise that it exists. Disablism is first and foremost about people’s attitudes: it does not only refer to consciously discriminatory behaviour, but also to the way that people unconsciously relate to disabled people. The unconscious part of discriminatory attitudes is much harder to tackle than conscious acts of discrimination, but both need to be equally targeted in the struggle for human rights. The vast majority of people would say that they are not against disabled people and that may be true. However, the majority still do not consider disabled people as equal, and cannot appreciate the obstacles that exist in society preventing disabled people from living ‘normal’ lives.[[12]](#footnote-12).

In his recent book Bob Williams-Findlay (2020), life-long disabled disability rights campaigner and theorist, having recounted his various personal and social struggles for equality, concludes by arguing against identity politics: ‘Disabilism, rather than “specific interests or concerns”, maintain disabled people’s social exclusion and marginalisation. The desire for inclusion isn’t wrong or idealistic, provided there’s an understanding of what needs to be done to make the world a home for all (p. 352).

To address the weakness of the Disabled Peoples’ Movement in the post-UNCRPD era and the lack of real progress towards implementing the paradigm shift, the Commonwealth Disabled People’s Forum (CDPF) was re-started at a Conference in New York during the UN Conference of State Parties, 13 June 2019 (States that have ratified the UNCRPD 184 at the last count[[13]](#footnote-13)). Of the 54 Commonwealth countries with an estimated 450 million disabled inhabitants the CDPF has continued to grow through proactive responses to Covid-19, developing policies and providing on-line capacity building.[[14]](#footnote-14)The CDPF has been clear from its inception that it is pushing for full implementation of the Human Rights for disabled people contained in the UNCRPD and the SDGs that this is a struggle against disabilism and has to be led by the thinking and voice of disabled people (not the many Non-Governmental Organisations who are now big players in various largely ineffectual projects) at a country and global level to improve things for disabled people. As made clear in the recent online training for disabled people capacity building course, CDPF[[15]](#footnote-15), when DPOs work with disability NGOs the slogan ‘Nothing About Us Without Us’ needs to be operationalised with the following five points being satisfactorily answered:

a Do they accept the leadership and thinking of Disabled People’s Organisations (DPOs)?

b Do they do everything they can to empower and build the capacity of DPOs?

c Do they reject the charity and medical model in favour of social/human right model of disability?

d Do they put their organisational, financial and training resources at the disposal of disabled people and DPOs?

e If the charity provides welfare services and treatment, do they still empower disabled people they work with?

f Do they allow disabled people and their organisations to lead, ‘Nothing About Us Without Us’ and not ‘steal our clothes’? (Slide 17 of PowerPoint, Module 1)

Unfortunately, the balance of forces is such that large international disability charities ‘for’ disabled people, while saying the right things, continue to take most of the money for bilateral and multilateral aid from Governments, employing mainly non-disabled people with token representation.

The International Disability Alliance works with the International Disability and Development Consortium (mainly NGOs) and various Governments, e.g. Canada, UK, Australia, Norway, Finland, Kenya, to drive forward implementation of disability rights with events such as the Global Summit on Disability[[16]](#footnote-16). What remains lacking is a strong united disability movement driven by local grass roots activists capable of holding their Governments to account. We are still a long way from disabled people collectively driving policy and implementation.

## World figures

Disablement, then, is a social process. As our paradigms have shifted and our thinking about disablement has improved, the numbers impacted in both UK and globally have increased. Many of the attempts to enumerate disabled people do not take account of this; instead, they view it as a medical problem or personal tragedy. In 1995, the United Nations estimated that there were at least 500 million disabled people in the world. This was made up of people with the following impairments: 55 million visually impaired (11 per cent), 70 million hearing impaired (14 per cent), 130 million with severe intellectual impairment (26 per cent), 20 million with epilepsy (4 per cent) and 160 million with some sort of mobility impairment (Disability Awareness in Action, 1995, p. 7).

The UN figures also revealed the major causes of impairment. These included: 100 million from malnutrition (20 per cent); 78 million from accident, war and trauma, including 20 million injured by land mines (15.6 per cent); 56 million from infectious diseases, such as tuberculosis, polio and leprosy (all of which are preventable) (11.2 per cent); 100 million from non-infectious diseases (20 per cent); and 100 million from congenital diseases (20 per cent). It has been estimated that 80 per cent of the impairments in the world are preventable, since they are caused by poverty, war, hunger and disease. The report gives many examples of self-help projects from around the world, where disabled people have managed to dismantle barriers to their inclusion (Disability Awareness in Action, 1995, pp. 7 and 9).

More recently estimates have increased, especially in the Global South. The World Health Organisation in 2011 estimated more than one billion disabled people, or 15 per cent of the world population total (WHO, 2011). This is now 1.2 to 1.3 billion people. The WeThe15 campaign[[17]](#footnote-17)launched to coincide with the 2021 Tokyo Paralympics is a recent attempt to challenge negative attitudes towards disabled people and change practices. Following a change in leadership of the International Paralympic Committee and a decision to collaborate with IDA and for the first time ever, IPC, Special Olympics, Invictus Games and International Committee of Sports for the Deaf collaborated to use the Games as a launch pad for wider disability equality.

The Sustainable Development Goals (SDGs) and the agreed indicators required a quantum move forward in recording disabled people in censuses and household studies and for data to be disaggregated. This presents a huge challenge to the statistical branches of many states. One of the challenges is that the notion of disability is complex and understood differently by individuals, cultures, specialists and academics all over the world. The UN’s Washington Group’s questions on disability status provide a solution to this with a standard global definition and method to measure disability.[[18]](#footnote-18)

Rather than use yes/no answers, The Washington Group’s questions ask respondents to position themselves on a four-point scale according to their level of difficulty and focus on six functional areas. Data collectors can ask the Washington Group’s questions without any medical knowledge, following short training on understanding stigma and discrimination.

India’s 2011 census reported 2.21 per cent of the population as disabled, but when respondents were asked the Washington Group’s questions, 16.7 per cent said they experienced severe difficulties functioning, while only 0.6 per cent responded positively to the census question ‘Are you disabled?’. The Washington Group questions have been challenged for weaknesses, for not taking into account the detail needed for identifying disabled children and not addressing psycho-social impairments. To give them their due, the Group have adjusted and produced a longer set of questions to include those impairment groups they missed over the last five years and developed and trialled a children’s set of questions. There now exist tools to elucidate the numbers of disabled people and for this to be usefully disaggregated in every country. Vital pressure is still needed from DPOs and others to get countries to fully adopt these tools in their censuses and surveys to provide much more effective rights and support for their disabled populations.

Countries (184 who have ratified) are obligated to carry out their responsibility to collect and disaggregate data in line with the UN Convention on the Rights of Persons with Disabilities (UNCRPD) under Articles 4 and 31. The 2030 Agenda for Sustainable Development clearly states that disability cannot be a reason or criteria for lack of access to development programming and the realization of human rights. The Sustainable Development Goals (SDGs) framework includes seven targets, which explicitly refer to persons with disabilities, and six further targets on persons in vulnerable situations, which include persons with disabilities.

The political commitments by 193 countries that committed to collect data on persons with disabilities and to disaggregate data by disability by adopting the 2030 Agenda for Sustainable Development and the global indicator framework that provides a guide on what data is needed to measure the implementation of the SDGs. Yet, overall official disability data is not reaching the global level to measure the SDGs and this must be addressed.[[19]](#footnote-19)

The Disability Data Tool Kit (2020), produced by the UN Stakeholder Group of Persons with Disabilities for Sustainable Development, International Disability Alliance and CBM, is a very useful resource that will be drawn upon widely.

The journey starts with the need for data, so that it can be used for evidence-based advocacy and to get the data for evidence, advocacy needs to happen to ensure that those responsible for collecting and gathering data do so. This is where important advocacy work at national and international level needs to happen to influence those required to create data. This is beginning and is foundational to all other efforts. The second aspect is once the data exists, it is vital to understand how to analyse, use and trust it for advocacy messaging. This is both to protect the integrity of advocates and to ensure that the change sought is based on an understanding of the reality of the situation and what works.[[20]](#footnote-20)

Comprehending these aspects particularly for those working at the grassroots level, to better understand the use of data in their advocacy is vital. Data literacy and turning data into a compelling message is a crucial part of gaining implementation of SDGs and UNCRPD.

## UK figures

The Labour Force Study and UK Census 2011 have adopted the Equality Act definition of disability: A person is ‘disabled if they have a physical or mental impairment that has a “substantial” and “long-term” negative effect on your ability to do normal daily activities’.[[21]](#footnote-21)Here substantial means ‘more than minor or trivial’ and long-term means ‘12 months or more’. People are judged without the impact of aids, medication or appliance, as the aim is to provide protection from discrimination. The Census and Family Resource Survey identify 11.9 million people in 2011 as disabled people out of a total population of 63,182,000[[22]](#footnote-22). This means that 18.85 per cent of the UK population counted as disabled.[[23]](#footnote-23)The number of people in the UK who reported a disability in 2019 to 2020 was 14.1 million. This means that nationally, 22 per cent of people have a disability.

The prevalence of people reporting a disability varied across the UK. In Wales, the proportion of people who reported a disability was 27 per cent, 5 per cent higher than UK national average. This was also the case in Scotland, with 25 per cent of people reporting a disability, 3 per cent higher than the UK national average. Within England, the North East region had the highest proportion of people reporting a disability in 2019 to 2020, with 27 per cent. The regions of North West, Yorkshire and the Humber, East Midlands and West Midlands reported 23 per cent, 1 per cent more than the UK national average. In the most recent survey year, London had the lowest proportion of people who reported a disability with 14 per cent, followed by the South East with 19 per cent.[[24]](#footnote-24)

The differences in disability reporting could be partially explained by the varying demographics in each region, e.g. percentage of older people, but also it bears the footprint of older primary industry (e.g. mining, farming, fishing) and secondary industry (e.g. manufacturing such as steel and car making) which creates much higher levels of long-term impairment. The proportion of the population varies by age. Eight per cent of children are disabled; 19 per cent of working age adults are disabled and 46 per cent of pension age adults are disabled.

A DfEE Workforce Survey (winter 2006) showed that only 50 per cent of disabled adults of working age (16 to 65 years old) were working or registered unemployed. This was up 10 per cent from 1995, and the increase coincided with a ten-year period of economic growth and the implementation of the Disability Discrimination Act. A slow growth continued in numbers of disabled people employed up until the Covid-19 pandemic, from 2.9 million in 2013 to 4.4 million in 2019. However, this can be largely explained by a growth in the numbers classed as disabled, but has gone up at a higher rate than for non-disabled people.

The UK Labour Force Statistics (DWP, 2019) show that between 2013 and 2019, the disability employment gap has reduced; with the latest data showing roughly half of disabled people were in employment (53.2 per cent) compared with just over four out of five non-disabled people (81.8 per cent). The employment gap was larger for disabled men than disabled women, with a 31.7 percentage point difference between disabled and non-disabled men, compared with a 25.0 percentage point difference for women; working disabled men were more likely to be self-employed (20.6 per cent) than non-disabled men (17.5 per cent); working disabled people were more likely to work part-time than non-disabled people, with 34.1 per cent of disabled people working part-time in comparison with 23.1 per cent of non-disabled people; the employment rate for disabled people with severe or specific learning difficulties was the lowest rate of any impairment (17.6 per cent) (ONS 2019)[[25]](#footnote-25). The latest employment gap data, though possibly understated due to Covid-19 was 28 per cent [[26]](#footnote-26).While the proportion of disabled people with a college degree increased from 15.9 per cent in 2013 to 23 per cent in 2019, but the qualification gap between disabled people and non-disabled people has not narrowed, still being nearly three times.[[27]](#footnote-27)

Although there were improvements in education for all school students in the ten-year period from 2004 to 2014 in terms of exam results, the gap between disabled students and those without special educational needs has widened. This continues with the 2020 statistics for 16-year-olds, despite teacher assessment replacing exams because of Covid-19, showing:

the attainment difference between pupils with SEN compared to pupils with no identified SEN remains the largest difference of all pupil characteristics groups. Pupils with SEN perform markedly worse than pupils with no identified SEN across all headline measures of attainment. In 2020, the difference in EBacc entry remained stable, however the difference between SEN and non-SEN pupils has increased for each attainment measure, with the difference increasing the most for the ‘achieving English and maths at grades 5–9’ statistic[[28]](#footnote-28).

‘Inclusion London’ (2015), drawing upon all available data, found that: ‘Disabled people continue to experience systemic barriers and inequalities across many areas of life from health inequalities to inaccessible transport. These barriers continue to undermine Disabled people’s human and civil rights and participation and inclusion in society’.[[29]](#footnote-29)

The 2008 crisis and consequent downturn have clearly hit disabled people harder than the rest of the workforce. A disproportionate effect on disabled people has been the impact of cuts in general and the Welfare Reform Act 2012 in particular. One researcher, Simon Duffy (2013), examining the cuts from 2010, found them to be unfair and disproportionately hitting people in poverty, disabled people and their families, demonstrating how they impact 19 times more upon disabled people than upon non-disabled people.

In June 2009 the UK government ratified the UNCRPD with four reservations or opt-outs on: Education, Article 24; Immigration, Article 18; Legal Capacity, Article 12; and Employment, Article 27. The UK government now has international treaty obligations on the rights of people with disability. Thus it would appear that the legal framework for disability equality and rights is firmly in place. However, implementation is another, matter dependent on wider changes in attitude in society.

The UK is signed up to the UNCRPD Optional Protocol. This means that individuals can take complaints to the UN Disability Committee for breach of the UNCRPD if all domestic avenues have been exhausted. If the Committee finds the complaint admissible, they will investigate and produce a set of recommendations for action. Disabled People Against the Cuts initiated and supported complaints under Article 19 (Independent Living), Article 27 (Employment) and Article 28 (Social Protection), and in particular over the closure of the Independent Living Fund and the adverse impact of the Welfare Reform Act to the Geneva-based UNCRPD Committee in 2013. The Committee accepted it as a valid complaint. As a result, the CRPD Committee deferred the general reporting obligation of the UK to the Committee until after the complaint. Members of the UNCRP Committee visited the UK, held 200 interviews and amassed 3,000 pages of evidence, and, after much time delay and obfuscation by the UK government, the Report was published in November 2016.[[30]](#footnote-30)The Committee found evidence of ‘grave or systematic violations of rights of people with disabilities’. The UK government did not accept the Report and issued a counter-report.[[31]](#footnote-31)However, the evidence is strong against the government and includes the following:

The state party has implemented a policy aimed at reforming its welfare system and the reforms have been justified in the context of austerity measures to achieve fiscal and budgetary policy consolidation.

The assumptions made under the policy include that: taxpayers need to be treated with fairness; large numbers of persons with disabilities have been relying and dependent on social benefits; persons are better off in work than on benefits; the dependency of persons with disabilities on benefits is in itself a disincentive to move them into employment; the number of persons with disabilities relying on social benefits were to be decreased; and tightening sanctions and conditionality of social benefits is a legitimate tool for incentivizing their moving into employment.

The impact assessments conducted by the state party prior to the implementation of several measures of its welfare reform expressly foresaw an adverse impact on persons with disabilities.

Several measures have disproportionally and adversely affected the rights of persons with disabilities.

Measures resulting in reduction of support provided to meet the extra cost of disability, denial of reasonable accommodation in assessment procedures and realization of the right to employment have had a discriminatory effect on persons with disabilities.

The core elements of the rights to independent living and being included in the community, an adequate standard of living and social protection and their right to employment have been affected: persons with disabilities affected by policy changes have had their freedom of choice and control over their daily activities restricted, the extra cost of disability has been set aside and income protection has been curtailed as a result of benefit cuts, while the expected policy goal of achieving decent and stable employment is far from being attained.

There is evidence that a large number of persons with disabilities have been affected (e.g. 13,900 persons with disabilities have lost their Motability schemes and therefore their adapted cars, upon implementation of Personal Independence Payment up to February 2016; 492,180 had been placed in the Employment and Support Allowance work-related activity group by the end of 2015; 41,792 Employment and Support Allowance work-related activity group sanctions were handed out up to March 2014).

Evidence gathered nationally by the Parliament, the independent monitoring framework, universities and research institutes and centres and independent experts, has documented adverse and disproportionate effects of measures on persons with disabilities.

The state party has not conducted a comprehensive human rights-based cumulative impact assessment even though reliable sources have indicated it is feasible.

The state party continues its policy of reducing social benefits of persons with disabilities as reflected in the Welfare Reform and Work Act 2016.

(UNCRPD Committee, 2016)

Ellen Clifford (2020)in her book *The War on Disabled People* recounts from the point of view of a leading activist and member of Disabled People Against the Cuts (DPAC) the vitally important task of telling what happened to disabled people in the UK after 2010 when the Government went to war against disabled people.

Prior to 2010, the UK government was known as a world leader in disability. A decision was made under the Coalition government and carried forward by successive Conservative administrations elected in 2015, 2017 and 2019 that progress had gone too far. The implementation of a fast turn was of international significance marking the first time in the history of modern social policy that things had gone backwards for disabled people. The way in which right wing politicians and the media achieved this-by creating a narrative that blamed disabled people themselves, purposively stoking fires of division and hate makes matters worse.

(p. 1)

Clifford points out that due to incorporation into local and central bureaucracies, attrition and identity politics, the old Disability Rights Movement was not able to challenge and the disability charities chose not to challenge as many had become financially dependent on the Government. A new form of resistance had to be built and DPAC grew from the experience of disabled people at the grass roots. Using direct action, lobbying, legal challenges, publicity, demonstrations and initiating the above Inquiry by the UN Disability Committee, they had considerable success, but most of the cuts went ahead. However, it broke down isolation and they saw that their struggle had to be linked to anti-capitalist struggles to create greater equality and say for ordinary people.

# The duty to promote Disability Equality

In 2005 the UK government introduced a duty to promote Disability Equality for all public bodies and a specific duty for certain bodies such as National Health Service (NHS) Trusts, schools, colleges, universities and local authorities to have a Disability Equality Scheme explaining how they would implement this duty (DRC, 2005). When carrying out their function, public bodies had to have due regard to the following:

• promote equality of opportunity between disabled persons and other persons;

• eliminate discrimination that is unlawful under the Act;

• eliminate harassment of disabled persons that is related to their disabilities;

• promote positive attitudes towards disabled persons;

• encourage participation by disabled persons in public life;

• take steps to take account of disabled persons’ disabilities, even where that involves treating disabled persons more favourably than other persons.

Furthermore, implementation was based on an understanding of the ‘social model’ of disability:

The poverty, disadvantage and social exclusion experienced by many disabled people is not the inevitable result of their impairments or medical conditions, but rather stems from attitudinal and environmental barriers. This is known as ‘the social model of disability’, and provides a basis for the successful implementation of the duty to promote disability equality.

(DRC, 2005, p. 172)

From December 2006 universities, colleges and secondary schools and other public bodies had to implement these duties. From December 2007 primary and special schools had to implement them. There was no comprehensive programme for training schools on these duties and most did not take them very seriously, as is evidenced by the scarcity of published schemes (Rieser, 2008b). In 2009 the Lamb Inquiry into parental confidence in the Special Educational Needs system recommended, based on evidence of a low take-up of the duties by schools, that Ofsted make compliance with equalities duties a limiting grade in inspections and that schools publish their Disability Equality Schemes on the internet. This was agreed by the Secretary of State (Lamb Inquiry, 2009).

In 2008 I carried out an action research project for the Secretary of State to ascertain if the new duties were improving the experience of disabled children in English schools. Working with Helping Empower Youth Activists (HEYA), we had 11 meetings with disabled children and young people.

We worked with 143 disabled pupils from 14 secondary schools, two academies, five special schools and five primary schools. We used a series of games and recorded views and filled in questionnaires. One activity was to get the young people’s views of their schools on a number of dimensions by using symbol cards that they could either move to or show. This produced a mixed picture and there was considerable variation across schools. Those where there was a higher proportion not liking playgrounds and corridors reported higher levels of bullying (Rieser, 2008b) (see Table 7.2).

There was evidence of some improvement in schools identifying barriers and changing practices to accommodate disabled pupils, but in too many cases little had changed, with the disabled pupil being seen as the problem. In individual interviews it became clear that those pupils who disliked the corridors and playground were the same ones who experienced bullying on a daily or weekly basis. In English schools 70 per cent of disabled pupils report bullying: twice the level for non-disabled children (DCSF, 2008). The EHRC report on ‘How fair is Britain?’ (2010b) increased this to 80 per cent.

The Equality Act (2010) both broadened and weakened the Public Sector Equality Duty. It extended it to cover more protected characteristics, while reducing the need to have a disability equality scheme to having one or more specific objectives covering all nine equality areas. However, the General Public Sector Equality Duty remains on all public bodies, including schools and colleges, to have due regard to the Section 149 Duty to promote equality in all its planning, policies and activities. This is strong legislation, but it is left to the individual or their parents/carers (if under 16) to enforce it. The many pressures facing the public sector, including financial ones, league tables and competition mean that this duty is often breached.

Table 7.2 What disabled pupils thought of their schools (per cent)

| Area of the school | Excellent | Good | Not so good | Bad |
| --- | --- | --- | --- | --- |
| The school building | 25 | 40 | 10 | 25 |
| Playtime | 33 | 39 | 16 | 12 |
| School dinners | 17 | 24 | 15 | 44 |
| Assemblies | 17 | 31 | 15 | 37 |
| School trips | 47 | 21 | 9 | 23 |
| PE and games | 29 | 43 | 12 | 16 |
| Lessons | 24 | 36 | 8 | 32 |
| Teachers | 19 | 46 | 5 | 30 |
| Teaching assistants | 40 | 39 | 7 | 14 |
| Other children | 22 | 28 | 18 | 32 |
| School council | 37 | 5 | 29 | 29 |
| School clubs | 25 | 25 | 26 | 24 |
| Corridors | 8 | 15 | 17 | 60 |

Source: 2009 Report for Secretary State World of Inclusion (www.worldofinclusion.com/res/impact/dpdes.doc).

# The history of disablement

The continuing inequality we face will not be rectified by ramps, lifts and accessible communications, or by the outlawing of discriminatory behaviour, welcome as these may be. The wellspring of our oppression comprises deeply held social attitudes that reflect generations of prejudice, fear and discrimination towards disabled people in education, work and social life. The main reasons are negative attitudes and stereotypes, which are based on untrue ideas that have been around for thousands of years, and which are amazingly persistent and manipulable.

We can, at any time, all become disabled, i.e. develop a physical or mental impairment. Perhaps the need to distance ourselves from this reality makes it convenient to rely on negative attitudes and stereotypes of disability. They are less troubling than accepting the individuality, the joy, the pain, the appearance, the behaviour and the *rights* of disabled people.

Work by anthropologists (Hanks and Hanks, 1948) has established that there is no one way that disabled people are viewed across a wide range of societies. Views ranged from high status to outcast. There appears to be an underlying economic basis, so in societies with more surplus produce, such as agricultural rather than nomadic or hunter-gatherer, there was more acceptance of disabled members of those societies. There was more chance of their being supported as there was surplus food. However, there were exceptions, and some evidence exists that hunter-gatherers have valued disabled members of their societies. A band of Aboriginal people from the Northern Territories in Australia carried a member of their band, who could not walk with them on their wanderings, for 60 years (Davis, 1989). Where an impairment was more commonly occurring, such as blindness in a Mexican village (Gwaltney, 1970), or in Martha’s Vineyard, an island off the US New England coast with an unusually high proportion of deaf people (Groce, 1985), the whole culture changed to accommodate guiding and signing, respectively. Although no systematic cross-cultural study of the position of disabled people has yet been carried out, it is clear that the individualized tragic view of disability prevalent in modern Western society is not universal.

## The ancient world

To understand the development of this particular view of disabled people we must go back to ancient Greece, to the beginning of ‘Western civilization’. In Greek mythology Zeus and Hera had a child, Hephaistos, God of Fire, who was born with a ‘club-foot’. He was thrown off Mount Olympus into the sea, but, being a god, he survived to return and become the butt of jokes of all the other gods (Garland, 1995). He was a forger of metal and as he grew up his sexual relations with women were frequently fraught with difficulty because of the attitudes of the other gods. His wife, according to Homer, was the beautiful Aphrodite, who deceived him by having an affair with Ares. Here, we witness one of the most pernicious myths about disabled adults – that they are incapable of adult sexual relations.

The Greek and Roman attitude was to worship and adore the body beautiful. This is exemplified by the many perfectly proportioned sculptures of the human body, bodies with ‘beautiful’ symmetrical features. In representations on vases, tablets, sculptures and so on, there are very few disabled people. The Olympic ideal was to aspire to be like the gods in physique, intellect and morals. This is still often apparent in the Olympic Games, where the Paralympics and Games for People with Learning Difficulties still segregate disabled athletes, although some physically and sensory-impaired people have recently competed in the main Games.

The cult of the body beautiful was put into practice, particularly among the patrician or ruling classes in ancient Greece and Rome. Aristotle wrote ‘that you should take your child off if they are imperfect and get rid of them’ (Garland, 1995, p. 15). The status of ‘child’ was not conferred until seven days after birth, so there was time to dispose of unwanted babies legally. In militaristic Sparta, children were the property of the state and inspected at birth. ‘If the child be ill-born or ill-formed’, the father was required to expose it at a chasm-like place called Apothetai or the Place of Exposure (p. 14). In Rome, disabled infants were meant to be drowned in the Tiber, and the games at the Coliseum put on to entertain and pacify the ‘mob’ included disabled children being thrown under horses’ hooves, blind gladiators fighting each other and ‘dwarves’ fighting women. The rest of the ancient world was not as proscriptive, but nevertheless, exposure was widespread.

Those with less significant impairments who survived generally led a half-life, disdained and ridiculed, often having to rely on begging. There were exceptions. Even in Sparta, King Agesilaos was afflicted with ‘congenital lameness’ but this acted as a spur to his ambition and he desired to be first in all things (Garland, 1995,p. 40). Clearly, then, exposure did not always occur, as parents do tend to love their children, and many disabled people survived infancy. In Rome, despite the dislike of and cruelty towards people with impairments, there is evidence that at least one emperor was disabled: Claudius may well have had cerebral palsy (*clauditas* in Latin means lameness). Claudius’ mother, Antonia, described him ‘as a monster of a man, by nature but only half done’ (pp. 40–42). Echoed in Shakespeare’s *Richard III*, this develops into an abiding stereotype as the evil and avenging man/monster.

## The Judaeo-Christian tradition

Another seminal source of thinking about disabled people was the Judaeo-Christian tradition that fundamentally, disability is a punishment for evil – ‘if humans are immoral they will be blinded by God’ (Deuteronomy, 27: 27); in Exodus (20: 5) God tells Moses that retribution for sin will be inflicted upon the offspring of the sinners for many generations. In the books of Exodus, Numbers and Deuteronomy, the people of Israel are repeatedly punished for their sinful ways through physical impairment (Rose, 1997).

The Jewish faith, however, has a more complex position, with some parts of the Talmud advocating disability as a holy state and a means of getting to heaven. Similar sentiments are expressed towards those who help disabled people. Some of this is reflected in the parables of the New Testament, but usually with Christ performing miracle cures. Rarely are disabled people accepted as themselves.

The Book of Leviticus (21: 16–20) has a clear message that impairment is unclean and polluting, and prevents disabled people from receiving sacraments:

And the Lord said to Moses none of your descendants throughout the generations who has a blemish shall draw near, a man blind or lame or one who has a mutilated face or a limb too long, or a man who has an injured foot or an injured hand or a hunchback or a dwarf, or a man with defective sight or itching disease or scabs or crushed testicles. He may eat the bread of his God, both of the most holy and of holy things, but he shall not come near the veil or approach the altar, because he has a blemish, that he has a blemish, that he may not profane my sanctuaries.

This message was taken seriously. Up until the 1950s people with learning difficulties were not allowed to receive certain sacraments in the Roman Catholic Church.

## The medieval period

Disabled people were treated in medieval Europe as both saints and sinners. On the one hand, they were ‘innocents unstained by normal and sinful human characteristics’ (Barnes, 1991, p. 12) who should be offered asylum and alms; on the other, they were evil changelings – the work of the devil (Haffter, 1968).

Martin Luther, the architect of the Reformation, believed that changelings had no soul and advocated that children so ‘afflicted’ should be taken to the river and drowned. Nevertheless, the bulk of disabled people born into feudal villages or acquiring impairments would have been accepted and did what they could, while those with more severe impairments may have been subject to infanticide.

Veterans of war were often treated better. The first record of a sheltered workshop in Europe was the Congregation of Three Hundred, established in France in 1254 for 300 crusaders who had had their eyes gouged out during the crusades (Ford, 1981).

At times of crisis disabled people were likely to be scapegoated as superstition took over, for example, during the Plague or during the Great Witch Hunt of 1480 to 1680. The ‘Malleus Maleficarum’ (‘the Hammer of Witches’), written by two priests in 1487, was a bestseller in Europe and went to 70 editions in 14 languages. It includes how you can identify witches by their impairments or by their creation of impairments in others; or giving birth to a disabled child. Between 8 and 20 million people, mainly women, were put to death across Europe and a large proportion were disabled. Three witches were recorded as hanged after an Oxford trial in 1613, one of whom was put on trial because she was a disabled person using crutches (Rieser, 1995, p. 6). More recent research on the treatment of people with learning difficulties, however, suggests that naturalistic accounts of learning difficulties and mental illness were accepted, rather than the disabled people being demonized (Neugebauer, 1996).

The ‘disabled witch’ comes through in the folklore of Britain and Europe. The Brothers Grimm collected the oral stories of Northern Europe and made them into their fairy tales. The witch in *Hansel and Gretel* is deformed, blind, ugly, disabled and carries a stick (this book has been adapted for use with children as young as two years old). There are also story-books that feature evil imps swapping healthy babies for disabled ones – changelings (Rieser, 1995, p. 5).

In her analysis of hate crime against disabled people, Katherine Quarmby (2011)goes back into history for an explanation of the persistent negative attitudes that spawn hate crime. Examining the witch hunts of 1645 and popular pamphlets in which ‘impairments, sin and witchcraft were inextricably linked in society’s collective unconscious’, she tells how Mathew Hopkins, self-styled Witchfinder General, found a destitute one-legged woman, Elizabeth Clarke, and forcibly questioned her to reveal her accomplices. Clarke along with 18 others was sentenced to death at Chelmsford Assizes. Clarke had to be helped to the scaffold due to her impairment. A noted sceptic of witchcraft at the time, Reginald Scott, said they were commonly perceived as ‘old, lame, blear-eyed, pale, foul, full of wrinkles […] lean and deformed showing melancholy in their faces’. Quarmby goes on to talk about the drowning of a disabled man nicknamed Dummy in Sible Hedingham in 1863 and then, in Lakeside Shopping Centre in March 2005, the drowning of Mark Watts, a man with learning difficulties, which his attackers filmed on their mobile phones having pushed him into the lake while other shoppers stood by and watched. These incidents remind us that the ‘other’ and ‘different’ can at any time be scapegoated unless we act consciously against it.

There are many pictures and stories from medieval times of penitent sinners. Groups of penitent ‘cripples’ are depicted trying to get alms and, if they wandered around long enough, feeling humble enough, then maybe they would make it in the next life. A very strong message therefore came across. Disabled people were often scapegoated for the ills of society, as in Brueghel’s painting *The Cripples*, where the fox tails denote wrongdoing. Outside any medieval church are the deformed ones, the gargoyles; and on the inside are the ‘perfectly formed’ pictures around the crypt.

Until the 17th century those disabled people rejected by their families relied upon the haphazard and often ineffectual tradition of Christian charity and alms – gifts for subsistence (Barnes, 1991, ch. 2). During the 16th century the wealth and power of the Church was greatly reduced due to the confrontation between Church and State in England. There was also a growth in those seeking alms due to a rise in population, poor harvests, the beginning of the commercialization of agriculture, and immigration from Ireland and Scotland (Stone, 1985). To secure the allegiance of local gentry and magistrates, the Tudor monarchs were forced to make economic provision for people dependent upon charity. The 1601 Poor Law marks the first recognition of the need for the state to intervene in the lives of disabled people. Some 200 years earlier, the Peasants’ Revolt of 1381 had led to a mandate to local officials to distinguish the ‘deserving poor’ from the ‘undeserving poor’. The bulk of relief went to the deserving poor in the form of ‘household relief to people in their homes. Segregation did not really emerge until the 19th century (Barnes, 1991, pp. 14–19).

Close examination of Rembrandt’s sketches reveals that the beggars are often wearing white headbands. This is because in 17th-century Holland the bacillus leprosy, brought inadvertently on the back of the ‘spice trade’ from colonies in the tropics, spread quickly around urban areas. An edict was passed by the state that all those who contracted it had to report to The Hague, and once their condition was confirmed they had all their worldly goods confiscated, had to wear a white headband, and they and their families had to rely on alms as penitent sinners. Those with leprosy had to live in segregated colonies and their only reward for penance was rehabilitation in heaven (Toth-Ubbens, 1987).[[32]](#footnote-32)

## The 18th and 19th centuries

The development of industrial capitalism and its inherent requirement for workers to sell their labour power meant that those with significant impairments were excluded from the labour market. Those disabled people who were able to work were forced to the bottom rungs of the labour market ladder (Morris, 1969, p. 9). As a result, disabled people came to be regarded as a social and educational problem and were increasingly segregated out of the mainstream in institutions of various kinds: workhouses, asylums, colonies and special schools (Oliver, 1990, p. 28). According to Finkelstein (1980), this is Phase 2 of disabled people’s development, the phase when we were separated from our class origins and became a special segregated group, with disability seen as an impairment, requiring segregation from the labour market as well as social restriction.[[33]](#footnote-33)

Throughout the 18th and 19th centuries the policy of segregating severely impaired people into institutional settings slowly spread. The main impetus was the change from working as groups or families on the land, down the mines or as cottage industry to factory work. Such work required set rates of working on repetitive tasks for long hours; time was money. By 1834, Poor Law household relief was abolished for the ‘non-deserving poor’ – the unemployed. The deserving poor were categorized – children, the sick, the insane, defectives and the aged and infirm, the last four being categories of impairment – and provision was uniform across the country. Deterrence built into relief as a principle of ‘least eligibility’ was introduced. This meant that those on relief would be less comfortable than an ‘independent labourer of the lowest class’ before benefits would be granted (Barnes, 1991, p. 16). Charles Dickens and others have vividly described the horrors of the workhouse. Charities increasingly set up asylums for the insane and then special schools for blind and deaf children. This role was taken over by the state from the 1890s (Hurt, 1988).

The ‘insane’, which included ‘idiots’, ‘lunatics’ and the mentally infirm, were, after the 1845 Lunacy Act, able to be detained on the certification of a doctor. This was based on a theory advanced by the medical profession that mental illness had physiological causes that were treatable. This marked the beginning of the medical profession’s state-endorsed involvement in the lives of disabled people (Barnes, 1991). This power is still exercised today; as a disabled person, if you want a Blue (parking privileges) Badge, Personal Independence Payment or other benefits such as Universal Credit supplement, you have to be examined by a doctor. Now Atos, a global leader in digital transformation, has won a contract to prove through a computerized test that many claimants with established work-limiting impairments are fit for work. This is leading to many being wrongly put on lower benefits and some committing suicide (*Guardian*, 14 February 2011). Interestingly, the same article reported that 40 per cent of such decisions were overturned on appeal.

Disabled people are not trusted in general and there is always a belief that people will pretend to be disabled to get benefits fraudulently, but this does not explain the continual checking of our impairments even when medical science has no solutions and our conditions are stable or deteriorating. In fact, the same *Guardian* article reported a fraud rate of less than 1 per cent despite outrageous headlines to the contrary in the *Daily Mail*. Far more disabled people who are entitled to benefits don’t claim them than the bogus claims from non-disabled people that are made; the latter, in reality, being rarities. This symbolic treatment of disabled people who are at the margins of the workforce very much defined who was part of the workforce and who was not (Oliver, 1990).

In the last quarter of the 19th century, another strand of thought became highly influential – the eugenics movement. This had and continues to have a disastrous effect on the lives of disabled people. Drawn from the ideas of Aristotle, eugenics thinking first wrongly applied Darwin’s theories of natural selection to ideas about racial degeneration and was then applied to disabled people. The birth of disabled children, it was claimed, would weaken the gene pool and outbreed non-disabled people. This, in turn, would weaken the European population in its task of colonizing and controlling the rest of the world (see chapters 3and 4, this volume, for a discussion of racism and imperialism).

## The 20th century

Traditional myths that there were genetic links between physical and mental impairments, crime, unemployment and other social evils were constantly proposed by the likes of Galton (1883, 1909), Dugdale (1895)and Goddard (1913), and many others. They wished to improve the British and American ‘races’ by preventing the reproduction of ‘defectives’ by means of sterilization and segregation. In the UK in the 1900s, pressure from eugenicists for ‘voluntary’ sterilization increased (Ryan with Thomas, 1987) (see the website www.eugenicsarchive.org for much more detail).

These ideas spread quickly to intellectuals of all political complexions as the century of science got underway: H. G. Wells, Sidney and Beatrice Webb, Bernard Shaw and D. H. Lawrence, W. B. Yeats, J. M. Keynes, Winston Churchill and Aldous Huxley, to name but a few.

If I had my way, I would build a lethal chamber as big as Crystal Palace, with a military band playing softly, and a Cinematograph working brightly; then I’d go out in the back streets and the main streets and bring them in, all the sick, the halt and the maimed; I would lead them gently, and they would smile me a weary thanks; and the band would softly bubble out the ‘Hallelujah Chorus’.

So wrote D. H. Lawrence in 1908 in a letter to Blanche Jennings (Boulton, 1979, p. 81). This was part of an elitist intellectual culture, which included a dislike for the industrial world and the social disorder it had spawned, and eugenicist views towards disabled people (Carey, 1992).

The Mental Deficiency Act of 1913 was the result of eugenicist agitation, and it led to the incarceration of ‘idiots’, ‘imbeciles’, ‘the feeble-minded’ and ‘moral imbeciles’, the last category usually referring to young people who had had illegitimate children. Many were incarcerated for life in sex-segregated institutions to prevent them from reproducing. At first it was argued that units or extra classes attached to ordinary schools were best, but soon the eugenicist view prevailed and the early part of the century saw large numbers of segregated schools for ‘crippled children, epileptics, educable morons and feeble minded children’ (Copeland, 1997, p. 714; see also Hurt, 1988).

A great wave of building ensued following the First World War with large institutions and colonies being erected on the outskirts of towns. Simon and Binet’s false science of IQ testing, refined by supporters such as Cyril Burt (1977), was developed to distinguish the educable from the ineducable. An IQ of less than 50 meant you were destined for a mental deficiency institution as a child and probably for life. It is estimated that 50,000 children with no mental deficiency were sent to these institutions prior to 1950, on the false diagnosis of doctors who, at this time, subscribed to bogus theories, such as that someone’s intelligence could be determined by their head shape and size (Humphries and Gordon, 1992).

Children perceived to be ineducable, including many with cerebral palsy, Down’s syndrome and speech impairments, went to junior training establishments right up until 1972. At that time, some 60,000 children joined the education system in severe learning difficulty schools. Today, many with the same conditions successfully attend ordinary schools. The history of people with learning difficulty has recently been developed as a learning pack for schools, students and the general public around the film *No Longer Shut Up*, based on the life of an activist and previous inmate of a long-stay hospital, by UK Disability History and the Open University. The more this hidden history is known and discussed the better chance there is of positive attitudinal change.[[34]](#footnote-34)

In the USA, compulsory sterilization was in wide use by the 1930s. Forty-one states had provision for the sterilization of the insane and feeble-minded, and 17 states prohibited people with epilepsy from marrying. In many states women born deaf were sterilized. Twenty-seven states still had these laws until very recently, though they were seldom enforced. In China, some 30 million people with ‘mental incapacity’ have been compulsorily sterilized under a law that was enacted in 1995. This is an abuse of their human rights and, as the *Guardian* reported in 1997, is a particular outrage, since it is known that many of these women have developed their condition from iodine deficiency in their environment.

Recently it has been reported that in Scandinavia and France, ‘mentally defective’ women were compulsorily sterilized up until the 1980s. This all took place despite the findings of a study carried out for the Wood Committee in 1929 which showed that only 7.6 per cent of patients in one particular asylum had ‘defective’ parents.

Disabled people are seen as a burden, and at times of economic stress this view intensifies. The Nazis, when they came to power in Germany in 1933, introduced a law for the Prevention of Hereditary Diseases that led to the forced sterilization of more than 300,000 people. Under the Third Reich, propaganda films were made to show how we were a burden on the state. We were the ‘useless eaters’, and we should be got rid of. In the beginning, voluntary euthanasia was advocated to end the suffering of ‘the incurable’, but this ultimately evolved into mass murder. In November 2003 the German government acknowledged that 240,000 physically and mentally disabled people were murdered in 1939/1940 at the hands of the doctors of the Third Reich in six so-called clinics, which were staffed by many of those who went on to run the concentration camps where six million Jews were exterminated (Burleigh, 1994). More recently in *War Against the Weak* (Black, 2003), the author estimates that more than one million disabled people died in this programme in the German Empire.

With cutbacks in the Welfare State, the eugenicist argument is currently undergoing a revival in Britain. A poll on *Good Morning Television* (GMTV) revealed that 86 per cent of people who rang in thought that a doctor was right to abort two disabled children. In Holland and Tasmania, laws have been introduced to allow voluntary euthanasia. This is indicative of the way in which, through history, people have been socialized to view disabled people. The medical ethics committees are allowing the Genome Project to map the seat of all genetic disorders. Soon science will have the capability to eradicate many forms of impairment. It remains to be seen whether society wishes to cut off such a great source of leadership, innovation and hope. Do we want a Society without Beethovens (deaf), Einsteins (dyslexic/autistic), Hans Christian Andersons (autistic), Stephen Frys (bipolar) or Tanni Greys (spina bifida)?

This brief excursion through the history of disabled people should cause us to ask if normality and uniformity are so important, or is it difference that makes life interesting? The medicalization of impairment ignores the social context. In 1972 in the UK, a child with Down’s syndrome (an extra chromosome) would be deemed ineducable. Today, many such children who have attended mainstream schools are able to sit seven or eight GCSEs and are accepted by their peers. What would their lives be like if prejudice and discrimination were to be eradicated? Yet the medical profession insists on genetically screening all pregnant women over 30 for Down’s syndrome with a view to termination if it is identified. We would not have Pablo Pinedas, a Spanish actor (Me Too/Yo Tambien, 2009) and teacher completing his Master’s Degree in Spain who has Down’s syndrome (Inclusion Now, 2010).[[35]](#footnote-35)

# The struggle for human dignity

The oppression of disabled people, over the years, has not gone uncontested. On the contrary, many disabled people have consistently struggled for human dignity and for inclusion in mainstream society. The National League for the Blind and Disabled and the British Deaf Association, for example, were both run by disabled people and, from the 1890s, campaigned for rights. In the 1920s, when unions of disabled veterans were formed all over Britain, sit-ins and occupations were held in an attempt to force the introduction of legislation for disabled people’s rights. In the 1920s and 1930s, there were hundreds of thousands of First World War veterans with no rights at all in the UK. Even those young people incarcerated in institutions for the blind or deaf had a culture of resistance; for example, when sign language was banned deaf pupils managed to develop their own pigeon sign language.[[36]](#footnote-36)

In 1944 the Disabled Persons Act was passed. This included a quota system, whereby 3 per cent of the jobs in any given business had to be allotted to disabled people. This was to accommodate injured war veterans, and was abolished by the Disability Discrimination Act of 1995.[[37]](#footnote-37)

In the 1970s, war veterans in the USA started the disability movement there and successfully campaigned until they achieved full civil rights legislation in the Americans with the Disabilities Act of 1990 (Dreiger, 1989).[[38]](#footnote-38)In the 1970s in the UK, the Union of Physically Impaired Against Segregation was formed. This was initiated by Paul Hunt, who lived in a Cheshire home that he called the new workhouse. He wrote a letter to the *Guardian* (20 September 1972) calling upon severely physically impaired people to form a new consumer group to put forward their views. This and a number of other organizations run by disabled people and formed in the 1970s amalgamated into the British Council of Organizations of Disabled People (BCODP). The Council, which supports the ‘social model’ of disability, now represents some 300,000 disabled people who all control their own organizations. The BCODP also linked a number of the local Centres for Independent Living and Local Coalitions of Disabled People (Campbell and Oliver, 1996). These organizations campaigned for full civil rights legislation. Fifteen attempts were made from 1980 to 1995 to get a Civil Rights Bill through Parliament in the UK. Instead, all that was achieved was the 1995 Disability Discrimination Act. The Direct Action Network of disabled people expressed the frustration of millions of disabled people in a series of actions that brought London and other cities and towns to a standstill. As a result, the Labour government set up a ministerial task force to advise on the implementation of full antidiscrimination legislation based on the ‘social model’ of disability.

Disabled people are still struggling for the rights to use public transport, to get into buildings, to go to school or college with their friends, to get a job and even to go to the cinema. In October 1998, the MP Glenda Jackson announced that £500 million would be spent on making London Transport buses accessible. In 2005, more was achieved with the introduction of the Public Service Duty to promote disability equality. In 2011, Disabled People Against the Cuts (DPAC) have taken on the mantle of DAN[[39]](#footnote-39)to challenge the human rights abuses of the Conservative–Liberal coalition and then David Cameron, Theresa May and now Boris Johnson’s Conservative government, who have continued the onslaught against disabled people.

Boris Johnson, now Prime Minister, in 2013 as Mayor of London gave the Margaret Thatcher Memorial Lecture at the Centre for Policy Studies (November 2013) aimed at the right-wing of the Conservative Party[[40]](#footnote-40)putting his recent claims to ‘level up’ in a clear elitist context:

Whatever you may think of the value of IQ tests it is surely relevant to a conversation about equality that as many as 16% of our species have an IQ below 85 while about 2% have an IQ above130…the harder you shake the pack the easier it will be for some cornflakes to get to the top. And for one reason or another, boardroom greed or, as I am assured, the natural and God-given talent of boardroom inhabitants – the income gap between the top cornflakes and the bottom cornflakes is getting wider than ever… No one can ignore the harshness of that competition, or the inequality that it inevitably accentuates, and I am afraid that violent economic centrifuge is operating on human beings who are already very far from equal in raw ability, if not spiritual worth.

Praising the wealthy and arguing they should flaunt their wealth more, Johnson continued:

It seems to me that though it would be wrong to persecute the rich, and madness to try and stifle wealth creation, and futile to stamp out inequality, we should only tolerate this wealth gap on two conditions. One, that we help those who genuinely cannot compete; and two, that we provide opportunity for those who can.

Much of the continuing pushing down on disabled people’s income and castigating those ‘cheating the system’ reflects this right-wing assault on disabled people and the poor and shows austerity to not be inevitable, but a political ideology.

# Recycling old ideas in the representation of disabled people

As disabled people, we often feel that the culture we are in characterizes us in a number of false ways that make us seem different to everyone else. Stereotypes of the disabled abound. Thus, there is the ‘super-crip’ or the disabled person who ‘triumphs over tragedy’. Have you ever noticed how often perfectly ordinary things that disabled people do become newsworthy – the blind mountain climber, the boy with cerebral palsy who walked one mile, or the deaf man who was a chess champion? These things are only seen as newsworthy because journalists have a view that disabled people usually cannot or should not be doing ordinary things. The 1996 London Marathon was advertised by Nike showing a man with no legs or arms. The caption was: ‘Peter is not like ordinary people. He’s done the Marathon’. This plays on two ideas: first, that we are not able to do things; and second, that we are objects of curiosity – ‘freaks’ who are worthy of public attention.

We are often referred to as ‘cripples’. This comes from an Old German word *kripple*, meaning to be without power. We do not like being called this. President Franklin D. Roosevelt, the only man to be elected President of the USA four times, had physical impairment, having had polio in both legs, and was unable to walk unaided. Yet he perfected ways of disguising it, such as never being photographed in his wheelchair. He once observed that ‘the American public would never vote for a president who was a cripple’. He may well have been right.

With the development of the printing press in 1480, at a time when most people in Europe could not read, cartoons and other graphic representations became popular ways of making political and moral comments to a mass audience. The old ideas of the Greeks became recycled: humankind was created by gods who were physically perfect. Since human beings were created in the gods’ own image, the less physically perfect were less worthy. Evil, moral weakness and powerlessness were depicted by caricatured disabled people. For example, in an attempt to discredit Richard III, historians portrayed him as a disabled and vengeful mass murderer. However, when his portrait that hangs in the National Portrait Gallery was X-rayed, it was discovered that the King’s hump had been added 60 years after his death. Modern film-makers often make their villains disabled. Little changes.

One need only look at pirates. From Lego pirates to Stevenson’s Long John Silver or Blind Pew, or Barrie’s Captain Hook in *Peter Pan;* nearly all have eye-patches, hooks and wooden legs. All these disabled pirates do not accord with historical reality. Pirates had a system of simple social security long before anyone else. They had common shares in the common purse so, if they were injured during the course of their endeavours, they would retire to a tropical island with as much money as they needed. They were unlikely, therefore, to go on trying their luck as an impaired pirate (Greenwich Museum, private exhibition, 1994). Yet in the 19th century a number of writers became obsessed with disabled and evil pirates. In previous centuries pirates had been socially acceptable as they plundered and built up the British Empire. For example, Daniel Defoe wrote a bestseller about a certain Captain Singleton, pirate, popular hero and, on his return, thrice Lord Mayor of London. But pirates outlived their usefulness as privateers who expanded the Empire, and after the Battle of Trafalgar, the Royal Navy could do the job on its own (Rieser, 1995).

Many charity adverts are designed to create fear. Take, for example, the one depicting a girl living ‘under the shadow of diabetes’. She probably did not even know she was ‘in a shadow’ until she found herself up on the billboards of England for three years. She was simply injecting insulin every day and that was all right. Other charity advertisements use black and white imagery to make us look pitiful (for a detailed analysis of how charities use images of disabled people to disable us, see Hevey, 1992).

There is, however, some cause for cautious optimism. The Invisible Children Conference, for example, jointly organized by Save the Children and The Alliance for Inclusive Education, was an exciting and thought-provoking day held in London on 1 March 1995 and attended by more than 150 key image-makers. The conference decided that ‘disabled people should be shown as an ordinary part of life in all forms of representation, not as stereotypes or invisible’. The 1 in 8 Group, which grew out of this conference, issued the following useful guidelines to the media. There are ten main stereotypes of disabled people; the disabled person as:

Pitiable and pathetic: e.g. charity advertisements and telethons, concepts like *Children in Need* and characters like Tiny Tim in *A Christmas Carol* or Porgy in Gershwin’s *Porgy and Bess*.

An object of violence: e.g. films such as *Whatever Happened to Baby Jane* or *Wait until Dark*, which set the style for countless TV films.

Sinister or evil: e.g. Shakespeare’s *Richard III*, Stevenson’s *Treasure Island*, the films *Dr Strangelove, Dr No, Hook* or *Nightmare on Elm Street*.

Curios or exotica: e.g. ‘freak shows’, images in comics, horror movies and science fiction, films such as *The Hunchback of Notre Dame* or *X-Men*.

Super-crip or triumph over tragedy: e.g. films like *Reach for the Sky*, the last item on the television news – featuring a disabled person climbing a mountain, for example.

Laughable: e.g. films like *Mr Magoo, Hear No Evil, See No Evil* and *Time Bandits*.

Having a chip on their shoulder: e.g. Laura in the film *The Glass Menagerie*. This is often linked to a miracle cure as in *Heidi* and *The Secret Garden*.

A burden/outcast: e.g. as in *Beauty and the Beast* set in subterranean New York, or the Morlocks in the *X-Men, You Before Me*.

Non-sexual or incapable of having a worthwhile relationship: e.g. Clifford Chatterley in *Lady Chatterley’s Lover, Born on the Fourth of July*, O’Casey’s ‘Silver Tassie’ or the film *Life Flesh*.

Incapable of fully participating in everyday life: our absence from everyday situations, not being shown as integral and productive members of society.

(Biklen and Bogdana, 1977, amended by Rieser and Mason, 1992)

# Conclusion: images and the way forward for disabled people

Shun one-dimensional characterizations and portray disabled people as having complex personalities and being capable of a full range of emotions.

Avoid depicting us as always receiving; show us as equals – giving as well as receiving.

Avoid presenting physical and mental characteristics as determining personality.

Refrain from depicting us as objects of curiosity. Make us ordinary.

Our impairments should not be ridiculed or made the butt of jokes.

Avoid sensationalizing us, especially as victims or perpetrators of violence.

Refrain from endowing us with superhuman attributes.

Avoid Pollyanna-ish plots that make our attitude the problem. Show the societal barriers we face that keep us from living full lives.

Avoid showing disabled people as non-sexual. Show us in loving relationships and expressing the same range of sexual needs and desires as non-disabled people.

Show us as an ordinary part of life in all forms of representation.

Most importantly, cast us, train us and write us into your scripts, programmes and publications.

(Rieser, 1995, p. 44)

Unfortunately, most children and young people still rarely meet disabled children in their schools and form their views of them mainly through the media. The inclusion of disabled people in producing and creating images, and the portrayal of disabled people as ‘real people’, is crucial.

With a very few welcome exceptions – such as the children’s television serial *Grange Hill, Sesame Street*, the BBC drama *Skallagrigg* or the serial drama aired on Channel 4, *ER*, or *Breaking Bad* on Netflix and the films *Four Weddings and a Funeral, Shine, Muriel’s Wedding* and *The King’s Speech, Yo Tambien, The Sessions, Margarita with a Straw* – disabled characters and images are largely absent, or when they do appear they are presented in a negative and stereotypical way. Change is slowly occurring. Thirty years ago Asian, Black and other minority ethnic people were in a similar position. Now the necessity for their inclusion is taken for granted.

Lack of portrayal of disability in our society is not accidental. Western culture from Greek and Roman times, reinforced in Renaissance Europe, has seen ‘the body beautiful’ as an ideal, and those with physical or mental ‘imperfections’ have been seen as being in receipt of divine retribution. Such ideas are deeply embedded in myth, legend and classical literature. Today’s digital entertainment culture reinforces the tendency to judge people by their appearance.[[41]](#footnote-41)In 2015, United Kingdom Disability History Month (UKDHM) held a conference on disability representation in the moving image and, although there is evidence of inclusion in television and film, there are still too many non-disabled actors playing disabled parts.[[42]](#footnote-42)

Over time, the British Broadcasting Corporation has commissioned a number of dramas – *Flesh and Blood* (2002), *The Egg* (2003), *Every Time You Look at Me* (April 2004) and *Don’t Take My Baby* (2015), and Channel 4 had *Cast Offs* (2015) and *Then Barbara Met Alan*” (2022). In 2020 marking 25 years since the adoption of the Disability Discrimination Act, the BBC ran a whole series of documentaries and dramas linked to Disability Arts Movement events. The programmes on TV and radio were unusual as they were written by disabled people and featured disabled actors/protagonists, e.g. *Crip Stories* [[43]](#footnote-43). All of these dramas included disabled characters as ordinary.

This is still unusual and apart from these occasional peaks of coverage, including Channel 4 on the Paralympics in 2012, 2016 and 2021, disabled people are still largely absent and exceptional, as the disabled writer Jack Thorne pointed out in his August 2021 Mac Taggert key note lecture at the Edinburgh TV Festival[[44]](#footnote-44). Although he had always pledged to further disabled people’s cause in his own writing, he felt he had failed ‘because the TV world is stacked against the telling of disabled stories with disabled talent. And that has to change’. He called for a quota to bring representation in line with 20 per cent of the population who are disabled.

As part of the European Year of Disabled People (2003), The British Film Institute and Disability Equality in Education collaborated to produce for teachers a website and a DVD examining how disabled people are shown in moving image media (www.redweather.co.uk/disabilityinthecurriculum).

In 2010, the first UK Disability History Month (22 November to 22 December and each subsequent year at this time) was held, providing a focus for schools, colleges, communities, trade unions and workplaces to hold events to examine our struggle for rights, the oppression we have faced and the need to continue to achieve equality. There have now been seven annual months, and a wealth of resources around different themes may be found on the website (www.ukdhm.org).

Each year, UKDHM produces a resource broadsheet and many other resources online to help understand disabled people’s history:

• 2010 Education (http://ukdhm.org/resources/2010-education/).

• 2011 Campaigning (http://ukdhm.org/resources/2011-campaigning/).

• 2012 Hate Crime and Changing Times Changing Lives (http://ukdhm.org/resources/2012-hate-crime/).

• 2013 The Struggle for Independent Living: No Return to Isolation (http://ukdhm.org/resources/2013-independent-living/).

• 2014 War and Impairment: The Social Consequences of Disablement (http://ukdhm.org/resources/2014-resources).

• 2015 Portrayal of Disability: Then and Now (http://ukdhm.org/resources/2015-resources/).

• 2016 Language and Disability (http://ukdhm.org/resources/2016-disability-and-language/).

• 2017 Disability and Visual Art (http://ukdhm.org/resources/2017-disability-and-the-visual-arts/).

• 2018 Disability and Music (https://ukdhm.org/category/resources/2018/).

• 2019 Resistance, Leadership and Culture (https://ukdhm.org/category/resources/2019-leadership-resistance-and-culture/).

• 2020 Access How Far Have We Come. How Far Have We Got to Go (https://ukdhm.org/category/resources/2020-access/).

# Covid-19 pandemic: A global barometer of how poorly disabled people are achieving their rights

The Disability Rights Monitor Report[[45]](#footnote-45)analysed over 2,100 responses to the survey which were received from 134 countries around the world. The vast majority were from disabled individuals and their family members. Very few governments or independent monitoring institutions responded. The report highlights four major themes which concur with what CDPF had found earlier:

• The egregious failure to protect the lives of people in residential institutions, which have become hotspots during the pandemic. Instead of prioritising emergency measures to reintegrate people into the community, respondents pointed out that many institutions have been locked down, with fatal consequences.

• Widespread, rigid shutdowns that caused a dramatic breakdown in essential services in the community. People could not access basic goods, including food, and supports such as personal assistance. Strict enforcement of these lockdowns by police and security forces has sometimes had tragic results.

• Serious and multiple human rights violations against underrepresented populations of disabled people: Women and girls have experienced a major uptick in violence, disabled children have been denied access to on-line education and homeless disabled people have either been rounded up, detained, or left completely to fend for themselves.

• A concerning trend of denying basic and emergency healthcare, including worrying reports about the adoption of discriminatory triage procedures: In some cases, persons with disabilities were directly denied access to treatment for Covid-19 because of their impairment.

The DRM survey collected over 3,000 separate pieces of testimony, many of which manifestly demonstrated a complete failure by states to adopt disability-inclusive responses. This was the case in many countries, regardless of their level of economic development, pointing to a collective failure on the part of leaders. Disabled People’s Organisation Monitoring in the UK and National Statistics tell a similar story.

Covid-19 certainly represents a ‘situation of risk’ and should have been addressed under Article 11 of the UNCRPD for people with mental, physical and cognitive impairments. Instead, we were often ignored, and early on politicians’ responses echoed eugenicist thinking of the ‘survival of the fittest’ with ideas of herd immunity and imposition of involuntary ‘do not resuscitate notices’ on disabled people described as ‘vulnerable’. The whole use of ‘vulnerable’ is a medical model description when policies and practices should have addressed the additional barriers that some disabled people were confronted by. While Covid-19 usually results in mild illness for most people, new variants caused by mutation can seriously impact some people across the whole population, but it is much more likely to cause serious illness and death for certain at-risk groups.

Persons with mental impairments, especially those with Down syndrome, already have shorter lifespans than the rest of the population and often have co-occurring physical impairments, such as circulatory conditions or diabetes at higher rates than the rest of the population.[[46]](#footnote-46)It is also thought that mental health conditions can increase the risk of infections including pneumonia. However, the exact numbers of persons with mental impairment and Covid-19 are presently unknown.[[47]](#footnote-47)There is evidence from Public Health England that people with learning difficulty were four times more likely to die of Covid-19 than the rest of the English population, at a younger age and in residential settings.[[48]](#footnote-48)The UK Office of National Statistics, as reported by BBC in November, had found from March to July some 30,296 of the 50,888 deaths were disabled people, with a disability accounting for 17.2 per cent of the study population, but nearly 60 per cent of coronavirus deaths.[[49]](#footnote-49)A separate study found learning disabled Covid-19 deaths ‘six times higher’ in England. Those under 30 had a death rate 30 times non-disabled peers. The study, which looked at deaths between 21 March and 5 June, found that 451 per 100,000 people registered with a learning disability had died with Covid-19 during that period. Due to gaps in the data, the researchers estimated that it could be as high as 692 per 100,000 – 6.3 times higher than the general population. The report suggests the huge disparity could be because people with learning disabilities are more prone to obesity and diabetes, which can increase the risk of dying from Covid-19.

The sorry conclusion to be drawn from the pandemic is that our Human Rights as disabled people are not being understood or respected. As the United Nations said early on in the pandemic:

**People with disabilities are not inherently vulnerable; it is attitudinal, environmental and institutional barriers that result in higher levels of vulnerability**. People with disabilities may have underlying health conditions that make them more susceptible to COVID-19, pre-existing discrimination and inequality means that persons with disabilities are one of the most excluded groups in terms of health prevention and response actions and economic and social support measures, and among the hardest hit in terms of transmission risk and actual fatalities.[[50]](#footnote-50)

In the next chapter I will examine how both traditional thinking about disabled people and the ‘social model’ impact upon the English education system, one which has grown out of the oppressive history of disabled people and ‘medical model’ thinking which have been and are predominant in special needs education. I will argue that inclusive education, rooted in an understanding of these diverse processes, is the way forward in eliminating both disadvantage and prejudicial attitudes.

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1. In the UK we call ourselves ‘disabled people’ because of the development of the ‘social model of disability’. The term ‘disabled people/person’ is used throughout rather than people/person with disabilities, except where Person(s) with disabilities is a title. This is because the author is an adherent of the social model of disability where the disablement is caused by socially imposed barriers beyond the person. It is therefore not logical to call disabled people who are disabled by society ‘persons with disabilities’. Others think person first language is more appropriate as the person comes first, and if that is their choice it should be respected. The author is of the view that what unites disabled people regardless of the type or degree of impairment is that they are faced with a common oppression, disablism. Disabled people come together to oppose and change this oppression. Thus, in solidarity, we are known as disabled people. In the 19th and 20th centuries, a disabled person’s medical condition was thought to be the root cause of their exclusion from society, an approach now referred to as the ‘medical or individual model’ of disability. Social exclusion led to inadequate policies and legislation, inappropriate attitudes, stereotyped media image, and inaccessible buildings and information. In the mid-1970s, a new way of thinking emerged from the disabled people’s civil rights movement, the ‘social model of disability’ or ‘barriers approach’ (Union of Physically Impaired Against Segregation, 1976). This stated that disabled people are those with impairments who experience barriers within society. It redefined disability as pertaining to the disabling effect of society, rather than the functioning of our minds, bodies and senses, by using the following definitions: (1) Impairment is a physical, mental or sensory functional limitation within the individual. (2) Disability is the loss or limitation or opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers. Therefore the term ‘disabled people’ was redefined by the movement to mean ‘people with impairments who are disabled by socially constructed barriers’. This ‘social model’ definition was adopted in 1981 by Disabled People International and its meaning was incorporated into the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). In the UK, disabled people are those with many different impairments: autism, deafness, blindness, bipolar, spinally injured, mental health issues, cerebral palsy, Down’s syndrome, etc. Challenging the barriers in society unites us. Claiming the label Disabled Person is an act of solidarity, being part of an oppressed minority, just as calling oneself a ‘Black Woman’, ‘Jewish Man’ or ‘Lesbian Woman’ are political and empowering labels. However, in other parts of the world, people first language had developed, so ‘persons with disabilities’ is still used throughout the UNCRPD. For those who choose to call themselves this, disability is not separated from their impairment. They want to be seen as people first, as disability is seen as a within-person problem. They do not wish to be defined/confined by their impairment. Although the oppressive and unequal treatment to which we are subjected is viewed as a breach of our human rights, the clear transition to viewing disability as something rooted in society and other than our impairment has never occurred. Without an understanding of ‘social model thinking’, it is reasonable to see disability as negative and wish to distance oneself from it by using ‘people first’. Some impairment groups, like those with autism, cannot separate themselves from the identity with their condition and so reject the ‘people first’ epithet, preferring Autistic People. Deaf people (with a capital D) view themselves as a cultural minority group and community, users of sign language and also reject people first language. However, people with learning difficulties or learning disabilities, as far back as the 1970s in Canada, rejected an imposed label such as ‘mentally handicapped’ and wanted to be known as People First organizations. Language can diminish or empower, and what is acceptable to various disabled people changes over time. When in doubt, ask the disabled people how they wish to be known. See. https://ukdhm.org/v2/wp-content/uploads/2016/02/UKDHM-2016-BROADSHEET-final1.pdf. [↑](#footnote-ref-1)
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13. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html. [↑](#footnote-ref-13)
14. www.commonwealthdpf.org. The CDPF has member organisations in 47 countries with 45 full member national umbrella organisations and a further 39 Associate regional or specific impairment Associate members and was recently recognised by the Commonwealth as an accredited organisation. [↑](#footnote-ref-14)
15. CDPF Online Disability Equality Capacity Building Course (2021), https://commonwealthdpf.org/training/. 14 Module Course with free access on-line with course books and follow up activities, lectures, film clips and interactive seminars in English which was initially run from, February to May 2021 with 428 participants from 41 countries that was both captioned, signed and audio described for access. [↑](#footnote-ref-15)
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28. https://explore-education-statistics.service.gov.uk/find-statistics/key-stage-4-performance-revised/2019-20. [↑](#footnote-ref-28)
29. Inclusion London Factsheet, 2015, www.inclusionlondon.org.uk/wp-content/uploads/2015/07/IL\_Inequalities-experienced-by-Deaf-and-Disabled-People-Factsheet-20152.pdf. [↑](#footnote-ref-29)
30. www.ohchr.org/Documents/HRBodies/CRPD/CRPD.C.15.R.2.Rev.1-ENG.doc. [↑](#footnote-ref-30)
31. www.ohchr.org/Documents/HRBodies/CRPD/CRPD.C.17.R.3-ENG.doc. [↑](#footnote-ref-31)
32. This book is written in Dutch, with an English summary. [↑](#footnote-ref-32)
33. In Phase 1, disabled individuals were part of a greater feudal underclass. In Phase 3, which is just beginning, disability comes to be seen solely as *social restriction*. The surplus value generated in capitalist societies, combined with modern technology, means that we can be exploited as workers by capitalism in much the same way as non-disabled people. However, it also means that we can make the case *not* to be segregated either in the world of work, or more generally in mainstream society. [↑](#footnote-ref-33)
34. There are education resources for schools and colleges on the history of learning disability from 1900 to the present day, 2016, www.open.ac.uk/health-and-social-care/research/shld/education-resources. [↑](#footnote-ref-34)
35. Interview with English subtitles, www.youtube.com/watch?v=74xGSYUs0YM. [↑](#footnote-ref-35)
36. The book *Out of Sight* contains first-hand oral histories and photographs of life in special schools and institutions in the first half of this century (Humphries and Gordon, 1992). [↑](#footnote-ref-36)
37. War and Impairment: The Social Consequences of Impairment (2014) UKDHM, http://ukdhm.org/2014-broadsheet/. [↑](#footnote-ref-37)
38. This is a good account of the international development of the Disabled People’s Movement. [↑](#footnote-ref-38)
39. Direct Action Network, www.worldofinclusion.com/res/qca/DAN\_To\_Boldly\_Go\_5.jpg. [↑](#footnote-ref-39)
40. https://www.theguardian.com/politics/2013/nov/27/boris-johnson-thatcher-greed-good. [↑](#footnote-ref-40)
41. Norden (1994)gives a fascinating account of how the image of disabled people has been developed through Hollywood, while Pointon with Davies (1997) provides a very useful handbook on how the disability movement has developed a critique and a response to the way in which disabled people are portrayed in the media. These ideas could also be useful to educationalists in the way they reproduce and interpret images of disabled people in the classroom. [↑](#footnote-ref-41)
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48. Deaths of people identified as having learning disabilities with COVID-19 in England in the spring of 2020, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/933612/COVID-19\_\_learning\_disabilities\_mortality\_report.pdf; Public Health England, Nov. 2020. [↑](#footnote-ref-48)
49. https://www.bbc.co.uk/news/uk-56033813. [↑](#footnote-ref-49)
50. United Nations, Policy Brief A disability-inclusive response to COVID-19, May 2020. [↑](#footnote-ref-50)