



UK Disability History Month 2013 Celebrating Our Struggle for Independent Living: No Return to the Institution or Isolation

CELEBRATING OUR LIVES • CHALLENGING DISABALISM • ACIEVING EQUALITY

The treatment of disabled people and thinking about physical and mental difference has varied over time. Overwhelmingly the experience has been negative, but there are always individuals and episodes of history that go against the grain, resulting in positive experiences for some disabled people. For Disabled People to live independently is now recognised as a Human Right under Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Article 19 UNCRPD http://www.un.org/disabilities/default.asp?id=279 "States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs."



Independent Living means having choices: the power to control what happens to us, sufficient support, being included and accepted into our local communities, education and leisure provision, having families and relationships. It does not mean doing everything for ourselves. The past

casts a long shadow over disabled people and our

struggle for equality and independence. Now the push for austerity is disguising an attack on equality. Particularly hard hit are disabled people, being 9¹ times more affected by the cuts than non-disabled people. Those with high support needs are 19 times more affected. False ideas about the majority of disabled people, as bogus claimants,

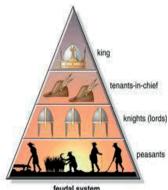


are fuelled by the press and encouraged by politicians leading to increased hate crime.

1 Simon Duffy 2013 'How cuts target disabled people' http://www.centreforwelfarereform.org/library/type/text/briefing-on-how-cuts-are-targeted.html

History tells us there is nothing new in this. We will briefly trace some of the most potent of these ideas and their origins, with examples of how we have challenged these and other barriers in our long history.

Medieval life (1100-1450) was harsh for all except for a small elite of royalty, barons and clergy. The vast majority of England's population was tied to the land under feudalism, labouring and fighting for their Lords. Charity was widely accepted as a Christian duty to help fellow human beings and this included 'old', 'infirm', young people and pregnant women. Monks and nuns in abbeys and monasteries provided small scale support for those not able to





William heals a blind woman, York, English Heritage

care for themselves. These became

the first hospitals. Attitudes to disability were mixed. People thought it was a punishment for sin or the result of being born under the hostile influence of the planet Saturn. Others believed that disabled people were closer to God. In Europe the church took control of discussions about illness and disability. The church's interest was based on Jesus' role as a miraculous healer and spiritual 'physician'. Monks and nuns would follow the seven 'spiritual works', involving feeding, clothing and housing the poor, visiting them when in prison or sick, providing counsel and burial services.



Illustration of Medieval life from the Luttrell Psalter, 1325

Much of the population, if they survived disease, famine, war and pestilence, would have had some degree of impairment. In Medieval England, the 'lepre' (leper), the 'blynde' (blind), the 'dumbe' (dumb), the 'deaff (deaf)', the 'natural fool' (a person with a learning difficulty), the 'creple' (cripple), the 'lame' and the 'lunatick' (lunatic) were a highly visible presence

in everyday life. For those with impairments that impeded their functioning many sought relief in pilgrimages to holy shrines of the Saints. It was widely believed that miracles, following Jesus' practices in the Bible, would be performed. Historians have found records from priests of many such miracles but there is no independent proof of these. There is no evidence of disabled people being excluded. Apart from times of crisis, they were



included in families and on farms, estates and villages.

There were disabled people of great accomplishment. Hermann of Reichenau (or 'Hermann the Cripple', left) was one of the most celebrated scholars of Latin, Greek and Arabic in the 11th century. He could scarcely move without assistance. King John the Blind (over leaf top right) ruled Bohemia from 1309 to 1346, and died in battle, fighting the English at Crécy.



Worthy Poor and Undeserving Poor

The disputed sketch (left) (1516), 'Cripples and Beggars', by Hieronymus Bosch or Bruegel the Elder, shows how common impairment was in late Medieval Europe. This sketch, also entitled 'All kinds of Beggars' Tricks' implies that the beggars were faking impairments which was a myth widely believed at the time. A popular poem read:

"Bold begging charms many a fool For begging has become the rule And ranks among our best professions."



As more labourers roamed, the fear of the 'sturdy vagabonds' (undeserving poor as they could work) led to deportation back to home parishes and punishment. If it was believed they were disguised as disabled people, the treatment was worse. The 'worthy poor' would be supported but the 'unworthy poor' were forced to work. This division was established by 1388 in the Statute of Cambridge and until the present there is a presumption that disabled claimants can be supported, whereas 'sturdy vagabonds' can work to support themselves.

The people, religious institutions, towns and cities of the Medieval period were pioneers in providing a specialised response to disability. Over the next 500 years this early professional approach would develop into our modern system of public services². The security of the feudal system began to fall apart with labour shortages caused by the Black Death (1348), a series of poor harvests as the weather pattern changed across Europe and a state of perpetual war led to a belief that black magic and evil forces were ever-present.

Martin Luther, founder of Protestantism, speaking of congenitally impaired children, said: "Take the changeling child to the river and drown them".

The Malleus Malleficarum ('The Witch's Hammer') was written by a priest called Kramer in 1486. This was a do-it-yourself manual for finding witches. Despite being outlawed by the church for 200 years, it became the second bestselling book in Europe after the Bible. The Medieval church dealt mainly with 'heretics'. As the new trade economy developed, the churches' traditional role in feudal Europe became threatened by cities and with the reformation the Church supported more witchhunts. Protestants often sought evidence of congress with the devil. If women were disabled or had a disabled baby, this was proof enough of witchcraft.



Three disabled witches hung, Oxford 1613

2 See http://www.english-heritage.org.uk/discover/people-and-places/disability-history/1050-1485/

Reformation and Closing of Monasteries When

Henry VIII split from the Roman Church he ordered the 'Dissolution of the Monasteries'. Across the country, religious houses were demolished and monks and nuns were driven out. The hospitals in these buildings were lost, along with the systems of care for sick and disabled people. For many, poverty and a life on the streets followed this destruction. A petition to King Henry in 1538 called for the re-establishment of the hospitals



The ruins of a monastery

that had been closed down. It complained of 'the miserable people lyeing in the streete, offending every clene person passing by the way'. Little new building took place in the next 30 years.

Disabled People at Court and in the Towns During the Tudor period, a handful of learning disabled people enjoyed a privileged life at court, with a 'keeper' who looked after them. These 'natural fools' were seen as an important source of wisdom and humour, a welcome contrast to the plotting and treachery at court. 'Jane the Fool' and the 'natural fool' Will Somer can be seen in this idealised painting of Henry VIII and his family.



The Reformation also challenged Christian charitable duty and the poor law was now needed to require local parishes to look after their 'needy' poor. The majority of disabled

A painting of King Henry VIII, his family and his two fools: 'Jane the Fool' and Will the 'natural fool'

people supported themselves. In the crowded and unhealthy cities of Elizabethan England conditions that resulted in long term impairment were very common. The city of Norwich carried out a census of the poor in 1570, gathering information about the lives of 1,400 of the poorest people in the city, including 63 disabled men and women with 'lameness' or 'crookedness' of the arms or legs, missing limbs, blindness or deafness.

Although poor, many were in work; the women were spinners or knitters, while some of the 'lame' men were labourers. William Mordewe, a blind baker, was still working at the age of 70, aided by his young wife Helen. Almost all of the disabled men and most of the disabled women were married to non-disabled people and many had children. People we would recognise today as having learning disabilities also lived in their communities rather than in institutions. Known as 'natural fools', 'innocents' or 'idiots', they were expected to stay with their families and work if possible. If the families were struggling because of ill health or extreme poverty, they might receive assistance from the parish³.

The Poor Law

A series of Poor Law Acts between 1495 and 1597 viciously punished 'sturdy vagabonds' who could be whipped and branded. The 'impotent poor' were viewed differently. "The person naturally disabled, either in wit or member, as an idiot, lunatic, blind, lame etc., not being able to work...all these... are to be provided for by the overseers of necessary relief and are to have allowances." This was funded by parish collections in church and dispensed as out relief to people in their homes. Relatives were expected to support those unable to support themselves at home. The Poor Law of 1601 marks the first official recognition of the need for state intervention in the lives of disabled people. Every parish was to appoint overseers of the poor, to find work for the unemployed and set up parish-houses for those

unable to support themselves. Most resources were directed towards domestic or household relief for people who were regarded as unable to work and were confined to the home. Segregation did not really start until 19th century, though some early workhouses were set up in the late 17th and 18th centuries, developing separate 'indoor relief'. From 1697 to 1810 anyone receiving poor relief had to wear a badge on their right shoulder. The badge, in red or blue cloth, was to consist of the letter P, with the initial letter of the parish e.g.



Early Poor house, Cheriton

Ampthill would be AP. Initially this was to identify recipients of parish charity. By 1697 it had acquired stigma and was to act as a further deterrent to claiming relief⁴.

Various reforms were introduced throughout the 18th century, giving more power to the representatives of rate payers, rather than the church and vestry. The 1723 Act introduced a legal framework for workhouses, which could be contracted or farmed out to private providers. A workhouse test acted as a deterrent, so relief could be limited to those desperate enough to accept the regime of 'indoor relief', in the workhouse. The 1782 Act aimed to organise poor relief on a larger scale. Parishes could form 'unions' roughly the size of County Hundreds. These could set up a common workhouse for a number of parishes, although only for the benefit of the 'old, the sick, infirm and orphan children'. Able bodied paupers were not to be admitted, but were found employment near their homes with land-owners, farmers and others who received allowances from the poor rates to bring their wages to subsistence levels.

In 1786, a total of 1978 workhouses with a capacity of 90,000 places were recorded. Total expenditure was £1.55million with 5% spent on workhouse accommodation and 94% spent on out relief i.e. employment for able-bodied poor and handouts to the impotent poor in their homes. In this year 306,000 people received some form of relief which amounted to 3.8% of the 8 million population⁵. After the Napoleonic wars there was a dramatic rise in unemployment and thus claimants; leading to popular concern, the Royal Commission on the Poor Law in 1832 and the New Poor Law in 1834. Numbers claiming relief were reduced, only to slowly rise in line with population increase. Expenditure rose dramatically again in the 1930s as the Great Depression hit⁶.

5 Webb, S and Webb, B (1929) 'English Poor Law Policy Part II: The Last Hundred Years' p1038-1040 quoted in Higginbotham p255. 6 Higginbotham P. (2012) The Workhouse Encyclopaedia

⁴ Drawing largely on Peter Higgenbotham (2012) 'The Workhouse Encyclopaedia' Stroud, The History Press. Also see History of workhouse website http://www.workhouses.org.uk/

New Poor Law and Less Eligibility Test (1834)

stated: "the situation of the able-bodied recipient of poor relief... shall not be made really or apparently as eligible as the independent labourer of the lowest class." This Poor Law created the mandatory workhouse structure. The Less Eligibility tests required that only those poor enough to deserve aid could enter, confined for 24 hours a day, separated from children, parents, spouses and subject to rigorous discipline and arduous labour. The workhouse life was



designed to be less desirable than that of the lowest paid independent worker, so that resources would not be greatly taxed. Very few able bodied people chose this; the great majority of inmates were aged, 'infirm' or children.

Large numbers had no choice but to seek welfare in the Workhouse and were depersonalised and treated very harshly. This engendered a negative view of disabled people amongst those who administered the first comprehensive state provision which



Devon County Asylum

according to today's definition. It was cheaper to confine those with mental health issues rather than the parish paying extra for the asylum, mandatory for each county. As the 19th century wore on, more disabled people were incarcerated and stigmatised in workhouses, never designed for them. Increasing numbers were admitted to asylums; some 100,000. Exceptionally, some philanthropists set up more humane institutions.

Social Darwinism or Eugenics began to dominate the thinking of the governing classes towards the end of the 19th century.

had a lasting attitudinal impact, mainly that we should be financially penalised. Many stayed away if they acquired employment or had family support. In 1862, an analysis of long term women residents in the country's workhouses, showed that 28% of inmates would count as disabled by today's standards⁷. In 1861, a parliamentary survey examined why people were staying over 5 years. 53 % were disabled



Meanwood Park Mental Deficiency Hospital 1921. 3000 'patients' at peak capacity.

People with learning difficulties living in the community were rounded up in special schools, long stay hospitals and colonies.

The British Eugenics Society led this movement, resulting in the 1913 Mental Deficiency Act, which sought to defend the British gene pool. By 1919, every council was rounding up 'ldiots, Imbeciles, feeble minded 'people and those who were drunk, unemployed, pregnant or criminal (perceived to have learning difficulties). All were placed for the whole of their lives in new, large long stay hospitals.



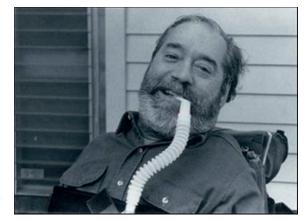
This was based on 'science 'such as IQ, proved

subsequently to be false. Eugenics was practised in many countries. Disabled people were prevented from marrying. They were incarcerated, sterilized and murdered. Black triangles signified their status. The Nazis of the Third Reich, with their T4 programme, killed more than 200,000 disabled people (labelled as 'Useless Eaters; Life Unworthy of Life'). The German People were softened up with lies and propaganda to see disabled people as a burden on the nation.

Ending the Institution With the founding of the National Health Service (1948), former workhouses, asylums and long stay mental deficiency hospitals were merged - with more than 250,000 inmates. In the 1950s, these hospitals and colonies became overcrowded as people lived longer. Some psychologists established that IQ was not fixed; that people with learning difficulties could learn new skills and could work.⁸ A number of scandals led to more public concern about long stay mental hospitals. The documentary Silent Minority aired on British television in 1981. It highlighted appalling conditions at Borocourt Hospital in Berkshire and St Lawrence's Hospital in Surrey. A process of running down large institutions and their replacement by the NHS policy of Care in the Community was implemented more substantially with the 1990 Act. Within 17 years, all the large institutions had been closed. Disabled people were living in small community homes or independently with support. However, many became homeless or imprisoned because of a lack of support, due to cuts begun in the 1970s (through till the 1990s).

Resistance Organisations of parents and self advocates, like People First and Mental Health Survivors, began to challenge the segregation of children and adults with learning difficulties. Organisations like the Camden Society, founded in 1966, pioneered moving from institutional care to supported living.

Supported living A disabled person gets the support they need to live in their own home. If the person's needs change the support can be changed. The support is tailored to the person's needs. This was part of a wider move towards independent living. Ed Roberts, (right) a post-polio quadriplegic, entered the University of California at Berkeley in 1964 and was a pioneer of the Disability Rights Movement. With the support of his organizer



8 http://www.thepsychologist.org.uk/archive/archive_home.cfm?volumeID=21&editionID=166&ArticleID=1433

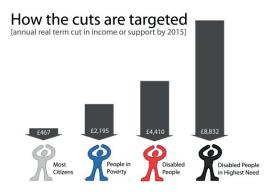
mother, Zona, Roberts fought the university and the State Department of Vocational Rehabilitation. He got the press to champion his cause. When Ed won this battle, a local newspaper carried the headline, 'Hopeless Cripple Goes to School.' Roberts said: "I am convinced that we are making the most profound social change that our society has ever known". The first centre for Independent Living, controlled by disabled people, was then set up in Berkley and the idea spread around the world.



The Disabled People's Movement sprung from resistance to the inhumane and degrading treatment we had experienced. The belief that the problem was rooted in us and our bodies (the 'medical model') gave way to the realisation that the problem lay in the external environment and societal attitudes (the 'social model').

The Union of Physically Impaired Against Segregation

and the British Council of Disabled People pioneered this 'social model' approach that was taken up by Disabled People International and some 30 years later forms the basis of the UNCRPD. In the UK, the Disability Discrimination Act and Equalities Act provide legal protection, but even with continuing resistance and support from allies these gains are being lost.



Austerity Measures levelled at disabled people are based on the historical lie that the majority of claimants are bogus scroungers. All objective figures show this to be untrue. Old stereotypes are often reinforced by the mass media. The austerity agenda threatens the gains in moving towards independent living. An unfair proportion of cuts are aimed at disabled people, some are even killing disabled people. The Daily Mail (30.08.12) established that an average of 32 claimants are dying every week after having their benefits withdrawn.

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