**LANGUAGE AND DISABILITY**

**FROM HOLOCAUST TO AUSTERITY BRITAIN[[1]](#footnote-1)**

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There are many reasons for saying that it is an honour and privilege to be asked to give a talk on language and disability in this city. I have learned a lot from living and working in Manchester for nearly 50 years, much of it relevant to the theme of this talk[[2]](#endnote-1).

First, I want to express my admiration for the work of the Manchester City Council Disabled Staff Group in raising disability awareness not only in the Town Hall but across and beyond the city.

Manchester has a fine record of disability advocacy: Loraine Gladwell has just written its history in connection with this month’s memorial lecture on Lord Alfred Morris - another Mancunian and the world’s first Disability Minister. He helped to establish the Hester Adrian Research Centre at Manchester University and I learned a great deal from him.

Today we can celebrate the pioneering work of the Greater Manchester Coalition of Disabled People and the leadership provided by Breakthrough, first by Loraine Gradwell and then by Michelle Scattergood who is now a Disability Commissioner at the Equalities and Human Rights Commission with Headquarters in Manchester -where else?

Right now, the disability movement is well placed to influence the plans and policies of the new Greater Manchester devolved authority. We need to be sure that the Mayor whom we elect next May doesn’t just consult disabled people but involves us in the implementation and monitoring of the new strategy. This is a unique opportunity not only to improve existing policy but to work with others to create a more inclusive community.

I can now say ‘us’ because I’m one of many local people with dementia who are involved in the planning of Dementia United which aims to make “Manchester to be the best place in the world to have dementia”[[3]](#endnote-2).

 I also have a having a significant hearing impairment which despite the latest technology makes it necessary to have support to be sure that I have both heard and understood your questions.

I’m too old to learn lip-reading but old enough to have witnessed or been involved in many changes in the language around disability since I first worked in what were then called *mental deficiency* hospitals in the 1950s.

My aim this evening is to take you through a high-speed language journey from the 1950s to today, with a few stops at landmarks along the way.

THE SOCIAL CONTEXT OF LANGUAGE

Before we set off, I want to stress the importance of thinking about language in a wider societal context.

The language used about disability and disabled people reflects some very powerful forces. These include:

* *Deep-seated personal, professional and public* *attitudes and values about disabled people in general and specific groups in particular*
* *The power imbalance between disabled people and the rest of the population*
* *The gross and growing inequalities* *between* *the haves* *and the have-nots*

The UK is near the top of the international inequality league table for the size of the gap between the income of its richest and poorest citizens. That gap is growing, despite a greater awareness that inequalities adversely affect the whole of society[[4]](#endnote-3)

The social model of disability highlights the obstacles that must be overcome to enable disabled people to participate in society on the same basis as others.

Some obstacles are easy to identify but difficult to overcome, as we see in the many inaccessible buildings, sport and recreational venues and public transport in many parts of the country, despite legislation which has been in place for decades but simply ignored.

I want to suggest that the biggest obstacle is the under-estimation of the capacity of disabled people by the general public and those who make continue to make decisions about us without consulting us.

One moment we are superheroes, next day we are work-shy benefit scroungers.

Disability hate crime has been rising year on year, especially since Brexit unleashed hostility and violence against anyone perceived as an outsider.

The new chair of the Equalities and Human Rights Commission – David Isaacs- has just called on the government to take these attacks more seriously.

Where is Teresa May’s commitment on the steps of Downing Street to reduce the inequalities in our society?

The government now wants to prioritise people who are ‘Just About Managing’. Where does this leave disabled people who can’t work or can’t find work and who have had to resort to food banks? Or those who have died or committed suicide after losing their benefits?

These attitudes and abuses need to be confronted – but how?

45 years after Alf Morris’s *Chronic Sick and Disability Act,* 21 years after the hard-fought 1995 *Disability Discrimination Act*, eight years of austerity cuts and more to come, what can we do to claim our basic human rights to citizenship?

My answer to this question is that we can make a start by claiming or fundamental human rights.

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Now is the moment to do it because the UK government is being held to account by the United Nations Human Rights Bodies for its implementation of the UN Convention on the Rights of Persons with Disabilities.

This Convention is the first international treaty to have been drawn up by the people it is designed to benefit and insists on the full involvement of disabled people in the national government’s implementation and monitoring of the Convention.

Until recently, the UK disability NGOs showed little interest in the opportunities for advocacy presented by the Convention, compared to their European counterparts. That has changed dramatically in the last two years.

The UN High Commission on Human Rights has just upheld a formal complaint against the UK government by Disabled People Against the Cuts. After examining hundreds of pages of evidence, the Committee agreed that the drastic cuts in benefits and supports for disabled people and in the funding available for public services were depriving disabled people of their right to independent living and participation in the community.

The government leaked what was meant to be a secret report to the *Daily Mail* and rejected the whole report and its recommendations.

 Next year it is the UK’s turn to be held to account by the United Nations Disability Committee for its implementation of the whole Convention.

LANGUAGE IS A HUMAN RIGHTS ISSUE

I want to suggest that we can think of the language around disability as a human rights issue. We can begin to do that in the context of the eight General Principles of the UN Convention.

1 Respect for dignity, autonomy, freedom to make choices independence

2 Non-discrimination by disability, gender, ethnicity, age

3 Full participation and inclusion in society

4 Respect for difference: acceptance of disability as part of human diversity

5 Equality of opportunity

6 Accessibility

7 Equality between men and women

8 Respect for the evolving capacities of children with disabilities and for the right to preserve their identities.

These words may sound like ‘pie in the sky’ or ‘pigs may fly’ but they come down to earth in the 34 Articles of the Convention.

It’s very important for Disabled Persons Organisations to take a lead in providing guidelines on unacceptable language and offering alternatives. There are already several language guides for the media which are ignored.

Dementia self-advocates have only just started to claim their human rights but have already published strong statements on acceptable and unacceptable language because they have missed out on all the developments that I am going to summarise for other disabilities[[5]](#endnote-4).

Bad care and bad language go together, so here are just a few examples of unacceptable language:

From the moment of diagnosis, we are always called *‘dementia patients’*, even though we may never meet another health professional other than our GP. We are people, not patients[[6]](#endnote-5).

We object to constantly being referred to as *‘sufferers’*. Although many people do have symptoms that cause suffering to themselves and to others, we suffer most from poor or non-existent services. e want services which would help us to meet our aim of Living Well with Dementia or even Beyond Dementia – but we don’t get them. We know from OECD research that “Dementia receives the worst care in the developed world”.

We object to politicians and researchers using military language about dementia – we’re not *demographic time-bombs or tsunamis.* We don’t believe in a *world without dementia* because people are living longer, especially in Low and Middle Income Countries such as China and India.

So we say Stop Promoting a CURE TOMORROW but spend money on CARE TODAY.

Eight years ago, the Japanese government abolished the word used for dementia because it was considered disrespectful and degrading, as it is English and in most European languages because it means ‘without mind’. When we say that someone is demented, we imply that they are out of control.

The new terminology is the equivalent of cognitive impairments which is widely used in American newspapers and magazines in place of dementia.

I want to distinguish between three different levels of language use in the wider disability world and give examples of how these have changed just in my life time.

LANGUAGE AT THREE LEVELS

-Terminology used to classify disabled people or used by professionals and decision makers

- Language that is used by the general public and in the media.

- Language that is recommend by organisations of disabled people or chosen by them.

Until 1948, we had *colonies* *for mental defectives*, who were classified as *idiots, imbeciles, feeble-minded and moral defectives.*

The Oxford English Dictionary defines a colony as:

*A body of people, especially if living more or less in isolation or in a special quarter.*

In 1948, the then new National Health Service took over these colonies, renamed them as hospitals and appointed medical directors and nurses, some of them with specialist training, as well as occupational therapists, clinical psychologists and social workers.

I started my training as a clinical psychologist in 1954 in a small progressive psychiatric hospital in Oxford and had placements in several hospitals and community services.

My long journey to human rights began when I was shocked by the inhuman conditions under which people lived in some of the long-stay hospitals that had been workhouses in the 19th century.

During the 1960s and 1970s there were many newspaper articles and books which drew attention to these conditions. There was talk of *snake pits, dumping grounds, warehousing, neglect and stigma.*

A particularly influential book was *Christmas in Purgatory[[7]](#endnote-6),* a photographic essay by Burton Blatt about Willowbrook, an institution near New York. It’s UK equivalent was a *Guardian* article by Ann Shearer headed: ‘A Mental Hospital on a Bad Day’.

The original title of Maureen Oswin’s account of hospital conditions for children with Profound and Multiple Disabilities was *Vegetables Don’t Cry[[8]](#endnote-7)* because that was the word used to describe them to visitors.

That book led to a national campaign to stop the admission of children to long-stay hospitals which reduced the number of children from 6000 to a few hundred because parents refused to follow advice by doctors to “put your child in a home and have another one”.

The last long stay hospital for adults with learning disabilities closed last year – this was Calderstones, near Blackburn - at one time one of the most progressive hospitals in helping its residents to live in ordinary houses in the community.

Its Chief Nursing Officer, Tom McLean told his staff that it was his mission to close the hospital and transfer all the residents to community services, each of them with a dowry to Social Services from the savings of closing the hospital – a policy agreed by Barbara Castle when she was Secretary of State for Social Services.

Borocourt Hospital in South Oxfordshire where I worked for five years in the late 50s and early 60s was ahead of its time in supporting its residents to live in the community and was certainly the first to negotiate places in local schools for some of its school age children and young people.

I soon realised that many adults had been sent to these hospitals long ago because of a combination of petty crimes or promiscuity with low educational achievements. Doctors still had to provide evidence of low intellectual ability to a central Board of Control who sent official visitors to the hospitals and usually reported that “the patients were well and happy”.

At that time, certification of mental deficiency was based on questions which involved knowing the distance from London to Edinburgh and the difference between a herring, a kipper, and a bloater.

This was also the period when the *Royal Commission on the Law Relating to Mental Illness and Mental Deficiency* was taking evidence. That Commission laid the foundation for the 1959 *Mental Health Act* and to the relocation of tens of thousands of people to community services.

But it also changed the terminology. I clearly remember the then Minister of Health proudly announcing to a large conference that *the mentally deficient of today will be the mentally subnormal of tomorrow”.* No one laughed but no one clapped either. It would be very different today.

Let’s stop the terminology train for a moment to reflect on the word *subnormal.* What word do we associate with subnormal?

For me, only ten years after the Holocaust it was *sub-human,* the word used in Nazi Germany to justify the gassing of 6 million Jews, including members of my family.

The gas chambers used in the Holocaust were first tested before the war on tens of thousands of disabled people who were deemed to be subhuman and unfit to live and were systematically murdered by the doctors entrusted with their care[[9]](#endnote-8) (Burleigh, 1997). Their relatives were told that they died of pneumonia and had to pay for a box of ashes.

Although idiot, imbecile and moron have long been officially abolished, they are still in use in everyday language as terms of abuse. It’s one thing to say ‘you idiot’ to a friend, quite another when it’s used by a politician to describe an opponent.

During the campaign for the Labour leadership, Owen Smith called Jeremy Corbyn a *lunatic,* followed by Tony Blair a few days ago, who called him a *nutter.* This has resulted in a formal complaint against the Labour Party by the Mental Health Resistance Network and Disabled People Against the Cuts.

But *Mong* and *Spas* can still be heard in playgrounds or shouted at children in public – perhaps because they’re naughty words.

Until 1971, children with an IQ test under 50 - administered by a school medical officer - were deemed to be *ineducable and* sent either to hospitals but increasingly to Junior Training Centres.

Stanley Segal, head teacher of a school for children with physical disabilities, led a brilliant *No Child is Ineducable* campaign – based not only on his book under that name but on his forceful advocacy at every level. I tried to persuade a MENCAP conference but some parents were doubtful: “Will teachers understand our children?”

In 1968 I came to Manchester to head a new research centre on teaching and learning: that was the beginning of a long partnership involving both special and mainstream schools: the then Director of Education, Dudley Fiske, picked up a phone to the Department of Education and got the money to include two research rooms in Melland School which was just being built.

During this time, subnormality continued to be used for legal purposes but was gradually replaced by mental handicap.

Learning disabilities later replaced mental handicap, even though in all other English-speaking countries learning disabilities refers to specific difficulties in learning to read or spell.

It seems we did a Brexit on terminology because the UN and the rest of the English-speaking world have been using *intellectual disability* for more than 30 years.

It would take me too long to describe the vast array of labels that followed the replacement ‘handicapped children’ by ‘children with special educational needs in the 1978 Warnock report and the 1981 Act. But I can strongly recommend Jenny Corbett’s *‘Bad-Mouthing: The Language of Special Needs[[10]](#endnote-9) –* a book that made me re-think my assumptions, attitudes and above all values and commit to human rights and social justice.

During the 1970s, ‘people first language’ began to be used because it was considered to be respectful, not just because it was politically correct.

*The* Mentally Handicapped became Mentally Handicapped People because they are people first and mentally handicapped second. Down’s Children became Children with Down’s Syndrome. Generalisations about disabled people should not be based on diagnosis because no two people with the same diagnosis are the same.

Neurodiversity

The Asperger’s community strongly rejects a disability identity. Instead, autism is seen as an expression of neurodiversity and they refer to the rest of us as neurotypicals. I don’t think this is labelling but a witty revenge on labellers. The late Gunnar Dybwad, a former President of Inclusion International, put it more simply “It’s normal to be different”.

One of the General Principles of the UN Convention is about respect for difference and acceptance of disability as part of human diversity.

People with dementia are attracted by the concept of neurodiversity because the longer you live, the more likely you are to experience problems in remembering, new learning and problem-solving which may lead to dementia.

So dementia too is on a spectrum from people who are just worried about their memory to those who can no longer recognise their relatives – that’s the image of dementia held by many members of the public and promoted by the press and the pharmaceutical companies.

Some of us have been accused in public of being imposters because no one with dementia could possibly give a public lecture:

Under-estimation is the daily experience of people with dementia and one of the reasons why we are claiming our rights on the same basis as other disabled people.

LANGUAGE PREFERRED BY DISABLED PEOPLE

So, what do disabled people say about how language should and should not be used?

Self-advocates never liked mental handicap because of the stigma around ‘mental’. When MENCAP refused to change its name because it would lose them donations, many self-advocates broke away from MENCAP and started People First Associations.

The Spastics Society changed its name to SCOPE and its constitution to enable half its Board Members to be people with cerebral palsy, as did several others. A vibrant self-advocacy movement started in Adult Training Centres which became Social Education Centres in the late 70s. It achieved a great success when the National Union of Students accepted them as full members.

Gary Bourlet who led this movement is now a member of the Disability Rights UK committee which is preparing evidence for the UN Disability Committee who will be meeting the UK government next year.

Organisations for rather than of disabled people struggled with terminology.

Canadian self-advocates succeeded in changing Canadian Association for Mental Retardation to Canadian Association for Community Living but it was a struggle. I was at one of the meetings where this was discussed and parents were asking ‘How will people know who we are? Will we lose our funding?’. Since then, CACL has gone from strength and provided world leadership on inclusive education.

The principle behind a change of name is that voluntary organisation should not be identified by an illness or diagnosis but by its mission.

The International League of Societies for Persons with Mental Handicap with whom I worked as a volunteer for 20 years finally became Inclusion International and now has self-advocates as Vice-Presidents and Council Members.

One of them, Robert Martin from New Zealand not only helped to write the Disability Convention but has just been elected to be a member of the UN Disability Committee.

All its 18 members are disabled and will soon be asking our government a lot of questions about their implementation of every Principle and Article of the Convention.

**Disabled People or People with Disabilities?**

In this talk, I’ve consistently used disabled people out of respect for the founders of the UK disability movement, many of whom I have known. I’d like to single out Vic Finkelstein with whom I worked in the 1970s in developing the first Open University course, then called ‘The Handicapped Person in the Community’.

This takes us back to the early days of the disability movement. Its founding fathers – because they were all male for quite a long time – and many of their followers rejected people first language and insisted on ‘disabled people’ rather than ‘people with disabilities’ because they were disabled by society more than by their impairments.

The original social model of disability focused on physical and institutional obstacles to participation in society but also included parents who over-protected their children, young and not so young.

The social model was contrasted with the medical or defect model which, in my view, has been over-simplified as a ‘fix it’ model which focused solely on the impairment and neglected everything else.

Later versions of the social model recognised and valued the support that could be provided by rehabilitation professionals such as occupational therapists, physiotherapists, speech and language therapists -all of whom are as essential to people with dementia as they are to people whose brains have been damaged by a severe stroke, a road traffic accident or a bullet through the brain.

The UN Convention doesn’t mention the social model but reflects this broader interpretation because it is concerned with a wide range of invisible disabilities:

- for example, mental health disabilities – called psychosocial disabilities in UN terminology- as well as a wide range of neurological conditions which now include dementia and autism as well as spina bifida, epilepsy and motor neurone disease, though not all these groups have claimed access to the Convention.

DISABILITY PRIDE

Disability Pride is in the great tradition of Liberation Movements in the 60s: the Women’s Liberation Movement; Black Pride, Gay Pride; even Silver Panthers- all driven by protest against discrimination, oppression, denial of citizenship and of the fundamental rights which were first proclaimed by the United Nations in the Universal Declaration of Human Rights – the first written words you see at the main entrance to the Town Hall.

Disability Pride takes many forms. One response to degrading language is to use even worse language to challenge it but at the same time to ask a fundamental question debated not just by disabled people but philosophers, psychologists, even economists.

In that spirit, Francesca Martinez asked *What the \*\*\*\* is Normal?*

In conclusion, I invite you to think about the language around disability in the context of each of the General Principles of the UN Convention: [www.un.org/disabilities](http://www.un.org/disabilities)

**Respect for dignity, autonomy, freedom to make choices, independence**

**Non-discrimination (e.g. age, gender, disability)**

**Full participation & inclusion in society**

**Respect for difference; acceptance of disability as part of human diversity**

**Equality of opportunity**

**Accessibility**

**Equality between men and women**

**Respect for the capacities of children and their right to preserve their identities**

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3. [www.dementiaunited.net](http://www.dementiaunited.net) [↑](#endnote-ref-2)
4. Wilkinson, R and Pickett, K. (2009) *The Spirit Level: Why More Equal Societies Almost Always Do Better.* London: Penguin. Stiglitz, J. (2013) *The Price of Inequality*: London: Penguin [↑](#endnote-ref-3)
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10. Corbett, J. (1996) *Bad-Mouthing: The Language of Special Needs*. London: Falmer Press. [↑](#endnote-ref-9)